



## Puertas de Diversidad Culturally Guided Interventions with Latinos

An HIV/AIDS Training Curriculum for Case Managers, Advocates, Social Workers, Substance Use Workers, and Other Service and Care Providers Who Interact with Latino and Hispanic Community Members Infected with and at High Risk for Transmitting HIV

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## Dear Trainer:

AIDS is seen as an urgent health problem in the Latino community, as reported in a series of surveys conducted among Latinos by the Kaiser Family Foundation since 1995. Yet many Latinos/Hispanics who are or who may be living with HIV infection have not been tested or are not using services to help them manage their infection.

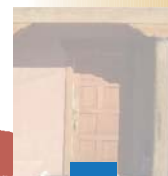
Since Latino/ Hispanic culture may influence the manner in which HIV/AIDS services are accessed or perceived, culture should inform how interventions are provided to assure that they are effective. The goal of this curriculum is to help providers across the continuum of care better serve the Latino community.

**Puertas de Diversidad: Culturally Guided Interventions with Latinos** is an HIV/AIDS training curriculum for case managers, advocates, social workers, substance use workers, and other service and health care providers who interact with Latino and Hispanic community members infected with and at high risk for transmitting HIV. Developed by members of the Latino/Hispanic community, including individuals living with HIV infection, the curriculum provides an overview of Latino/Hispanic culture and how it may affect living with HIV infection, followed by an overview of HIV; what it is, how it works, how to test for it, and how to treat those infected with it. Using case studies, the third section applies culturally guided intervention to meeting Latino/Hispanic individuals' needs, and to helping persons with HIV learn self-advocacy skills. Appendices offer training resources and reference materials, a glossary, and referral resources for a range of services in the Rocky Mountain Region, as well as on the Internet.

In this curriculum, both commonly used generic terms, "Latino" and "Hispanic," are used to connote ethnicity, heritage, nationality group, lineage, country of birth, or primary language of a person or person's parents or ancestors before their arrival in the United States. Terms appear as used in reference sources. However, the generic terms do not adequately capture or reflect the diverse populations and individuals who are the intended beneficiaries of this curriculum. "Latinos" and/or "Hispanics" may be of Mexican, Puerto Rican, Central or South American, Cuban, Dominican, Spanish or other origin. They may be of any race, may or may not be U.S. citizens or speak Spanish, and may have vastly different immigrant, settlement and social histories in the United States.

This curriculum is designed to serve as a teaching tool and resource reference for individuals providing services to HIV-infected Latino/Hispanic persons. It promotes cultural competence in service interactions, and hopefully will inspire further skill development in this area.

Thank you for your work in the field of HIV and for your contribution to improving service access for all persons living with HIV infection. Please use this curriculum in further opening Puertas de Diversidad.





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## INTRODUCTION

### Objectives

Upon completing the introductory section, learners will be able to:

- Present a context for implementing culturally guided interventions
- Discuss the impact of HIV in the Latino/Hispanic community
- List some factors that may influence Latino/Hispanic perceptions of HIV
- Present the importance of cultural awareness

### HIV/AIDS in the Latino/ Hispanic Community

#### Epidemiology Summary

National and state data are tracked and reported by the Centers for Disease Control (CDC) and the Colorado Department of Public Health and Environment, respectively. The following information is derived from reports of cases documented through 2001.

A clear trend in the HIV epidemic in the U.S. is the increasingly disproportionate number of persons of color with HIV relative to their numbers in the general population. While only 14% of the total U.S. population, Hispanics comprised 20% of AIDS cases reported in 2001, and the number of AIDS cases per 100,000 population (AIDS case rate) was 28, almost four times higher than the rate among non-Hispanic whites. Persons in the African-American community continue to be the most disproportionately affected individuals in the HIV epidemic.

The disproportionate impact of HIV among Hispanics is greater for women than men. This in turn affects the number of HIV infections among Hispanic children, resulting in disproportionately higher rates of pediatric HIV in this group relative to non-Hispanic whites. Adolescents are similarly affected. Adding to the problem may be the finding of a 1995 Youth Risk Behavior Survey, conducted by the CDC, in which Hispanic students in grades 9-12 reported the lowest use of condoms by themselves or their partners during their last sexual encounter.

In Colorado, Hispanics are 17% of the total population, but represent 19% of the recent HIV epidemic, and the state case rate for Hispanics is 11.5/100,000, nearly twice the case rate among whites.

The primary risk factors for acquiring HIV are the same for Hispanics at the national and state levels. Among men, same sex transmission is the most commonly reported route of transmission (41% nationally, 65% in Colorado), though injection drug use is a steadily increasing risk factor (32% U.S., 44% CO). In Colorado, persons reporting injection drug use as their risk factor seem to be more likely to live in rural areas.

Among women, heterosexual contact is the main transmission risk (43% U.S., 49% CO [this figure includes all women with HIV]), followed by injection drug use. However, heterosexual risk may be secondarily related to injection drug use through sexual contact with injection drug users.

Of great concern is the percent of persons who are getting tested for HIV late in their illness, as indicated by development of a diagnosis of AIDS within a year of testing





positive for HIV infection. The average time between infection and a diagnosis of AIDS is 8 to 10 years without treatment. While this testing delay has been demonstrated across the spectrum of HIV-infected persons nationally and in Colorado, the percent of late diagnosed individuals is greater in communities of color, with almost half of Hispanics testing late.

Deaths due to HIV disease have been declining over the past several years, largely due to the effectiveness of newer drug therapies, as well as to the effect of long-standing prevention programs. However, this decline has not been experienced equally by all affected groups, with slower rates of decline in communities of color. HIV remains a leading cause of death in the Hispanic community. Late diagnosis of HIV infection, as discussed above, as well as the slower decline of the epidemic in Hispanics, may in part be explained by differences in access to or utilization of care.

### Latino/Hispanic Perceptions of HIV/AIDS and Influences on those Perceptions

Since 1995, the Kaiser Family Foundation has conducted a series of national surveys to learn about views and attitudes towards HIV. The most extensive report on the responses from the Latino community, published in November, 2001, noted the following concerns and views:

- While 40% of Latinos rated HIV as the most urgent health problem facing their community, 64% identified HIV as a

more urgent health problem than it was a few years ago. Among interviewees, lower income and less education correlated with higher concern about HIV as an urgent health problem.

- Latinos were more likely to know someone with AIDS, and were more concerned about their own chances of getting infected. This was particularly true for younger persons.
- Latinos were knowledgeable about the basic facts of HIV transmission, including the increased risk associated with having another STD. Older Latinos (over 30) and Spanish speakers were more likely to be misinformed about risks of casual contact.
- More than four in ten Latinos reported having been tested for HIV, either because they requested it or a medical professional told them the test had been done. Some believe it is a routine part of medical exams. Of those who tested, one-third did not discuss results with a medical professional.
- The 53% who reported they had not been tested for HIV felt they were not at risk, did not know where to go, feared needles or were concerned about confidentiality.
- Individuals with less education were less likely to have been tested for HIV. Those with more education reported greater concern about the stigma of having an HIV diagnosis.
- Latinos were aware of therapies to help treat HIV infection, but less than half of all Latinos surveyed were aware of interventions to prevent vertical (perinatal) transmission of HIV.
- HIV information sources for Latinos





include television (69%) and magazines or newspapers (58%), radio (46%, higher than among whites or African-Americans), church, family members and friends.

- More than one-third of young Latinos (18-29), had talked with their doctor or other health care provider about HIV. More than half had initiated the conversation, seeking information about testing, personal risk and prevention. Older Latinos were less likely to talk about HIV with health care providers.
- Generally, Latinos reported wanting information about how to talk with family, partners and doctors about HIV, and where to get tested, how testing is done, what the results mean, and if they are confidential.
- The vast majority (98%) of young adults believe high school sex education classes should include information on how HIV and other sexually transmitted diseases are spread, and how to protect against those diseases.

These highlights offer valuable guidance in developing services to reach the Latino population. The detail of the report, supported by other studies, reveals that factors such as income, education, religion, gender, age, region, ethnic identity and language spoken produce differences in perceptions, knowledge, attitudes and behaviors among Latinos. This wide diversity within the Latino community influences risk behaviors and the tendency to seek services to manage HIV infection. Within a population or community, services must be tailored to the unique circumstances of individuals in that community.

## Importance of Cultural Awareness

Because people function according to their unique cultural orientation, every interaction between people is a cross-cultural experience for both people. Each person brings to the encounter his or her own culture, which includes language, values, customs, diet, familial and gender roles, beliefs, and traditions. In order for communication to take place, there must be an effort to incorporate the differences into the interaction. The more diverse the cultural backgrounds of the persons interacting, the more important it is to be able to listen and learn for communication to happen. In health care, such cross-cultural communication skills are essential to facilitate access to and delivery of meaningful and beneficial health care.

The largest and fastest growing ethnic group in the U.S. is the Latino/Hispanic community. According to U.S. Census figures, the Hispanic population increased by 58% nationally and 42% in Colorado between 1990 and 2000. Therefore, cross-cultural interactions between Latinos and persons from other groups are a common occurrence. The impact of this growing population on health care is bound to be profound, and the delivery system must be able to meet needs of an increasingly diverse patient population. Thus, understanding Hispanic cultural values, family dynamics, health beliefs and practices, as well as the process of acculturation, increases health care providers' effectiveness.





## A PROFILE OF the LATINO/HISPANIC COMMUNITY

### Objectives

Upon completing the Latino/Hispanic overview section, learners will be able to:

- List some attributes of the Latino/Hispanic population
- Discuss some Latino/Hispanic cultural values that influence their experience in health care settings

### History/Origins

Fifteenth century Spanish explorers discovered what we know today as Cuba, the Dominican Republic and Haiti. In the following years, Spain expanded its empire into the "new world." Intermarriage produced persons of mixed blood, or *mestizos*. In Mexico, Conquistadors claimed treasures for the Spanish crown and brought Catholic missionaries to forcibly convert indigenous inhabitants. Some indigenous populations became extinct during this period. Spanish culture spread from Mexico to Central and South America, and over what is now the southwest United States. Early Spanish settlements were established in what became Florida, New Mexico and California.

Hispanic immigration was influenced by early U.S. military actions in Mexico and Central America. In some cases, the U.S. declared its right to territory occupied by Mexico. Mexico lost much of its northern territory to the United States following Mexico's war to gain independence from Spain. The 1848 Treaty of Guadalupe Hidalgo annexed parts of AZ, CA, CO, NV, NM, TX, UT and WY, thus imposing a new border between Mexicans on either side of

the new U.S. territory. This resulted in Mexican migration back and forth across the border, which continues today. Another effect was that many "colonized" Mexicans felt they would be better off by adopting the culture of their conquerors. Immigration may also be the result of Central American and the Caribbean people fleeing civil war and/or economic instability in their countries.

According to a publication by The National Alliance for Hispanic Health, in the 1950s and 60s, "Hispanics" tended to organize around their unique national identities. When the term "Hispanic" came into wide use as a reference to all Spanish-speaking ethnic subgroups in the 1970's and '80s, new national organizations brought together the numerous Hispanic subgroups into a more unified voice around social, civil, and political causes.

The term "Latino" was introduced in the late 1980s as a reference to persons living in the United States whose ancestors were from Latin American countries in the Western Hemisphere. It was considered a more linguistically accurate term ("Hispanic" is an English-language term not generally used in Spanish-speaking countries), and more culturally neutral. However, neither generic term adequately captures the diverse and rich heritage of many to whom it is applied, including those of Indian or African heritage. In current use, both terms include individuals of varied racial backgrounds, and are often used interchangeably. Some Latinos/Hispanics feel strongly about which term they prefer, some reject both, preferring to identify by their national origin, and still others use both terms varying use depending on context. One danger of using broad, generic terms is





that they may more readily lead to stereotyping across a diverse population. It is important to recognize and respect that **identification with one's heritage is of personal significance, and individuals identify themselves differently. Therefore, it is important to find out what term of identification is preferred by persons with whom one interacts.**

## Population Characteristics

Statistical data on numerous aspects of the U.S. population is collected and reported every ten years by the U.S. Bureau of the Census. Reports vary as to exactly when the term "Hispanic" was introduced into government vocabulary, though it was during the 1970s, as previously mentioned. It was adopted by the census as a generic term intended to include all individuals who came from, or had parents from, Spanish-speaking countries. With that precedent, the term and its concept have become widely used in social science research, policy development, and community and political organizing.

While there is some ability to learn about distinct populations within the umbrella category, as a general rule, the data reported under the heading "Hispanic" include a richly diverse combination of ethnic, racial and minority individuals. They may be Mexican, Mexican-American, Puerto Rican, Cuban, Central or South American, Spanish-speaking Caribbean, or even Spanish, and include individuals from all social strata, economic means, educational levels, citizenship and language use, whether they are from multi-generational families of U.S. citizens, recent immigrants, or undocumented workers. This generic labeling

may conceal diverse social histories and identities that truly characterize a significant segment of the U.S. population. It also implies greater shared similarities across all "Hispanics" than is the case. For example, persons of limited socioeconomic means have more in common with one another regardless of race or ethnic group assignment, than with all other members of their assigned race or ethnic group.

While having a unified identity can serve some positive purpose, it is important to keep this melding of many people in mind when reviewing the following data, which is either from the 2000 Census, or the 2002 Epidemiologic Profile of HIV and AIDS Cases in Colorado.

**Group identity.** The largest segment of the Hispanic population in the United States and Colorado is Mexicans and Mexican-Americans, often self-identified as Chicanos. This includes approximately two million seasonal and migrant workers. While Colorado is not in the top ten states with respect to number of Hispanic residents, it does rank sixth nationally in percent of total state population that is Hispanic. From 1990 to 2000, the U.S. Hispanic population increased by 58%, and in Colorado there was a 42% increase in the same time period. The Urban Institute estimates that 5.1% of Colorado's population may be non-citizen immigrants who are predominantly Hispanic.

**Age.** The Hispanic population in the United States is relatively young compared with other groups. A majority is less than 40 years old, 36% are under age 18, and only 5% are aged 65 or older. A similar pattern is seen in Colorado. It is relevant to note that according to the CDC, one in four Americans newly infected with HIV is less than 22 years old, with young people of color comprising two-thirds of all reported cases among 20-





24 year olds. This trend has serious implications for the relatively young Hispanic population.

**Economic status.** Three times as many Hispanics live below the poverty level (23%) as non-Hispanic whites. Unemployment among Hispanics is twice that of non-Hispanic whites. More than a third of the Hispanic population is uninsured.

**Education.** Fifty-seven percent of the U.S. Hispanics are high school graduates, with 30% having degrees or training beyond the high school level. However, only one third as many Hispanics attain a bachelor's degree or greater when compared to non-Hispanic whites. In Colorado, the high school drop-out rate for Hispanics is high.

**Employment.** The majority of Hispanic men work as laborers, in production or the service industry. Hispanic women are employed in sales, service and as laborers. Men, women and children labor as seasonal or migrant workers, of whom 71 % and 95% respectively are Hispanic. Seasonal workers typically live in the same place, and their sole source of income is from seasonal work. Migrant workers travel from their home country, move around following work opportunities, and return to their country.

**Fertility.** The 1997 census reported that the fertility rate (average of 2 births per 1,000 women) among Hispanic women was the highest among all groups: black women had an average of 1.5 births per 1,000 women, and white women had an average of 0.2 births per 1,000 women.

**Health Issues.** The two leading causes of death among Hispanics are the same as among non-Hispanic whites, heart disease

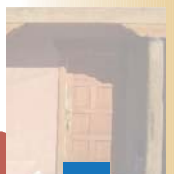
and cancer. Other health issues are stroke, diabetes, tuberculosis, environmental risks, obesity, depression and stress. Even as leading causes of death in Hispanics, heart disease and stroke rates are lower than for African-Americans or non-Hispanic whites. Average life expectancy for Hispanics is high at 75 years for men and 83 years for women.

The specific health risks for seasonal agricultural and migrant farmworkers merit special attention. Living conditions create greater susceptibility to tuberculosis. Exposure to chemicals in pesticides and herbicides is associated with several illnesses. Water supplies are often contaminated, also contributing to various illnesses.

**Incarceration.** Of all individuals in custody of the Colorado Department of Corrections in 2000, 28% were Hispanic, while only 17% of the general population is Hispanic.

**Language.** Spanish is the most widely spoken second language in the United States. While 72 % of Hispanics report that they speak English well, Spanish is used more often at home or in social situations. Variations in Spanish use or fluency relate to background, residence, age, education, acculturation or social and political factors. Many Hispanics speak no Spanish. Knowledge of or fluency in Spanish is most common among older people, recent immigrants, and Hispanics who live along the Mexican border. U.S. born-Hispanics, particularly younger people, use Spanish less frequently than their immigrant counterparts.

**Sexuality.** Sexuality is very private and personal in Hispanic culture, a practice sometimes referred to as "sexual silence." Sexual issues are often not discussed





between sexual partners, and it is considered particularly inappropriate for women to raise the topic. However, in a seeming contradiction, when there is a need to introduce sexual content, especially for health reasons, women/ mothers in a family are likely to be more receptive to those discussions. A double standard allows Hispanic men to have sex outside of marriage. In Hispanic culture, the behavior of male homosexuals is often a source of shame for themselves, their relatives, and friends. It is important to note that labels designating sexual orientation may not have the same meaning to Hispanic individuals as they do to their non-Hispanic white counterparts.

**Access to Health Care.** Latinos are more likely to be uninsured or publically insured, e.g., receiving Medicaid, than are whites. Most health care is obtained through public clinics or through emergency services. Transiency and/or lack of health care benefits in employment also influence access to care. Undocumented Hispanics may worry about risks of being detected if they seek health care.

**Drug injection.** Some Hispanics in the United States, especially recent immigrants, share needles and syringes for activities other than drug use; for example, for injecting medications, such as antibiotics and vitamins, at home. They may not buy new needles as needed because of cost, stigma, confidentiality or no perception of risk.

## Cultural Values

For Hispanics, as with any ethnic group, cultural context is the foundation of community. However, the extent to which the cultural values influence behavior, belief or attitude may depend a great deal on the degree to which someone has acculturated, or assimilated. In

acculturating, one borrows from the predominant culture in his or her surroundings and integrates those traits with one's own cultural identity and traditions. Assimilation is a process of replacing one's original cultural traits with those of the dominant culture. Studies indicate that Hispanics are less likely to assimilate than were many earlier immigrant populations to the U.S.

Several factors influence acculturation, or the development of biculturalism (incorporation of mainstream culture without losing Hispanic culture traits). They are: birthplace; generational status, including years of U.S. residence and age at immigration; language preference, occupation; education; proximity to country of origin and frequency of visits. Acculturation may be driven by the need to "fit in" and thus secure a job and ensure financial security, or to avoid discrimination or ostracism. **Acculturation can have a profound effect on behaviors and interactions. Thus it is important to become aware of the extent to which an individual has acculturated to the environment in which he or she must live and work.**

Identity is often defined by the place one grew up. Thus, immigration can cause loss of identity, and transformation. Acculturation, which is the process of transformation or adaptation to a different culture, can be stressful. It may manifest clinically or behaviorally as depression or substance abuse, for example.

Literature in the field of cultural competency is consistent in identifying the following basic cultural values among Latinos/Hispanics.

**Familismo/Familia.** Latinos/Hispanics include many people, beyond the parent and





sibling nuclear family, in their extended families, including grandparents, aunts, uncles, cousins and *comadres/compadres*, close friends and godparents (*padrinos*) of the family's children. Extended families provide a large supportive network for its members. Within that family network, emphasis is placed on interdependence over independence, affiliation over confrontation, and cooperation over competition. Decisions are often weighed in relation to the risks and benefits to the family.

Latino/Hispanic family relationships are generally hierarchical, with status and authority determined by age and experience; males hold the highest status.

Specific attributes have been associated with traditional gender roles in Hispanic families. Women are expected to be sentimental, gentle, intuitive, impulsive, docile, submissive, and dependent (*marianismo*). They are likely to put the needs of all others ahead of their own needs. Men are expected to be rational, profound, strong, authoritarian, independent, and brave (*machismo*). The term *machismo*, as used within Latino/Hispanic culture, refers to a male's love and affection for and protection of the family, as well as dignity, honor and respect for others. Traditional gender role behaviors of men and women may be different in public than at home. It is not unusual for roles to be reversed, or for power to be shared.

- Patients may delay treatment decisions to seek advice and opinions from family members. Family members may accompany a patient on medical visits.
- Due to his status in the family, the cooperation and/or approval of a male partner may be important to initiating treatment or other interventions.

- Female patients may be reluctant to disclose pertinent information during a clinical history and physical.
- Inappropriate use of a child as an interpreter disrespects authority and disrupts family roles.

*Respeto.* *Respeto* (respect) dictates appropriate deferential behavior towards others based on age, sex, social position, economic status, and authority. Formality is seen as a sign of respect. First names should not be used without permission. Older adults expect respect from those younger, men from women, women from men, adults from children, teachers from students, employers from employees and so on. One way to demonstrate *respeto* is to avoid eye contact with authority figures. However, an authority figure is expected to look directly at the person with or about whom (if an interpreter is involved) he/she is speaking. A Latino/Hispanic may avoid disagreement or withhold questions as an expression of *respeto*.

- Patients may not ask questions or admit confusion about treatment instructions.
- Patients are not likely to directly express negative feelings, which may get expressed indirectly through non-compliance or termination of care.

*Personalismo.* Latinos/Hispanics tend to stress the importance of *personalismo*, personal rather than institutional relationships. Thus, continuity of care is very important. Hispanics expect those with whom they interact to be warm, friendly, and personal, and to take an active interest in their personal lives. *Personalismo* also has a physical dimension. An interaction is more comfortable when the people involved are physically close to each other.





- Patients are much more likely to use community-based services.
- Patients establish loyalty to health care providers and may follow their provider if they relocate nearby. Patients may discontinue care if the health care provider leaves the area.
- Patients may offer small gifts to providers; refusing them may be taken as personal rejection.

*Confianza* (trust) results when Hispanics sense that they and their culture are respected. This includes allowing community priorities to guide interactions. Showing personal interest in Hispanic individuals helps win their trust. In the health care setting, establishing *confianza* with a patient will more likely result in willingness of the patient to follow advice and treatment plans.

- Monolingual Spanish patients may assess trust by carefully noting non-verbal messages from non-Spanish speaking providers.
- Interactions may become more informal, warm and intense once a patient senses trust has been established.

*Espiritismo*. In traditional Hispanic culture, spiritual healers play an important role in addressing health concerns. *Curanderas*, *espiritistas*, or *santerias* are generally associated with Latinos/Hispanics whose cultural identity is Mexican, Puerto Rican and Cuban respectively. Health is a holistic matter in which spirit, mind and body work together, and all must be cared for. Physical illness may be seen as the result of a strong emotion, such as anger or sadness, or a lack of balance and harmony. Spirituality can coexist with strong religious beliefs.

- Some patients will seek the services of folk healers while simultaneously receiving mainstream professional health care.
- An illness may be attributed to *mal ojo* (evil eye) or *envidia* (envy)

*Fatalismo* (Fatalism) A commonly held belief among some Hispanics is that events are meant to happen to them because of luck, fate, or powers beyond their control, rather than being dependent on their own behavior. This may include a belief that negative events, such as illness, are God's way of testing an individual. Fatalism may be reinforced through strong religious beliefs, and may promote relinquishment of responsibility. Cultural fatalism tends to be more common among individuals of lower socioeconomic means.

- Patients may feel helpless to do anything about an illness, or feel that interventions cannot change fate.

*Religion*, like culture, can be a pervasive force influencing the behavior of Hispanics. In general, Hispanics are deeply religious. The church, regardless of denomination, serves as a guide for attitude and behavior, as well as a focal point for social interaction among Hispanic families. Some influential Catholic values are enduring human suffering and self-denial.

- Religious beliefs may prevent persons from seeking health care.
- Prevention messages may conflict with strongly held religious convictions.





## Suggestions for Health Care Providers Working With Latino/Hispanic Individuals

- Try to learn Spanish. Speaking in Spanish facilitates a greater level of comfort in disclosing feelings and behaviors for Spanish-speakers.
- Use Spanish words you know when comfortable. Strive to spell and pronounce names correctly.
- Ask for explanation or clarification of terms that are not familiar.
- Sit or stand near the patient. More than a handshake away is too far.
- Spanish is Spanish, with regionalisms and slang just as in English, so avoid asking if a person speaks “Mexican” or “Puerto Rican.”
- Use qualified interpreters with a background relevant to the setting of an interaction (e.g., medicine, social service). Children should never be asked to act as interpreters for their family.
- Validate when using a translator, by acknowledging the patient, maintaining eye contact with the patient. Assure understanding of complaints, issues, and responses. An inappropriate response may indicate a misheard question or comment.
- Encourage patients to ask questions. Explain thoroughly and confirm understanding.
- Allow family members and/or friends to accompany a patient. The family is generally an individual’s primary source of support, and extends beyond a “nuclear” family. Extended family members may also wield power.
- Identify and address the matriarch and patriarch, i.e., decision-maker or spokesperson.
- Be formal in interactions with older Hispanic patients.
- Check to make sure recommendations will fit into the patient or family lifestyle. (who holds the power to implement, can they afford it, etc.)
- Accommodate patients of whom personal/private questions are asked (use a separate room, during a lab procedure).
- Avoid use of labels. Refer to behaviors.
- Explain all exam procedures and purpose before initiating patient contact.
- Make chart notes as cues to family names or special events. Follow up with a mention or inquiry in a subsequent visit.
- Medical model diagnoses may not offer the same explanation for symptoms as the patient perceives. Validate patient views.
- Foster psychosocial support and reduce stressors.
- When appropriate, use or refer to traditional remedies or healers.
- Facilitate personal connection with a new health care provider if a patient must be transferred.
- Listening is KEY.





## HIV OVERVIEW

### Objectives

Upon completing the HIV Overview section, learners will be able to:

- Define HIV and AIDS
- Discuss HIV transmission and list prevention strategies
- Describe treatment interventions for HIV infection

### HIV BACKGROUND

#### What is HIV? What is AIDS?

HIV (human immunodeficiency virus) is the virus that causes AIDS (acquired immunodeficiency syndrome). The virus spreads from person to person primarily through blood-to-blood and sexual contact. Over time, HIV weakens the immune system, leaving the infected person susceptible to many opportunistic infections and diseases. The appearance of any of these infections and diseases signals AIDS.

The Centers for Disease Control and Prevention (CDC) first described the syndrome that came to be known as AIDS in 1981 when unusual cancers and rare opportunistic diseases appeared among a group of young men, primarily homosexuals. Further reported cases also linked the presenting symptoms to transfusion recipients. HIV-1 is the most common serotype in the United States. HIV-2 predominates in Africa. Both are transmitted via the same routes.

HIV disease includes the continuum from infection with HIV through asymptomatic and

symptomatic illness, ending in death. It is a slowly progressive disease that follows generally predictable stages of changing chronic illness. A person's disease progression may depend on biologic, virologic and treatment factors. The course of illness is different for every person, and infected individuals can do a great deal to manage their illness and influence quality of life.

Without treatment, the average length of time from infection to first, pre-AIDS symptoms of disease is from 8 to 11 years. Available treatments can lengthen the time to an AIDS diagnosis. Although the years of early infection are characterized by clinical latency (inactivity), HIV remains active in reservoirs such as lymph glands.

In HIV disease, before an AIDS diagnosis, a patient may have one or more of the following symptoms caused by primary seroconversion, or worsening immune function.

- diminished appetite,
- lymphadenopathy (swollen lymph glands),
- diarrhea (loose, frequent stool),
- fatigue (low energy level, weariness),
- neuromotor or neurocognitive changes (physical or mental slowness),
- night sweats, or
- weight loss.

According to the Centers for Disease Control and Prevention (CDC), a diagnosis of AIDS is established in the presence of HIV infection, and if the CD4+ cell (T-cell) count is less than 200 cells/mm<sup>3</sup>, OR if one or more AIDS-defining conditions are present (see Table 1). These conditions are also used for epidemiological statistics and to meet the requirements for some government benefits and services.





Table 1. 1993 AIDS Surveillance Case Definition

AIDS-Defining Conditions	
CD4 + T-cell count of $< 200\text{mm}^3$ or $< 14\%$ proportion CD4 + T-cells/total lymphocytes	Kaposi's sarcoma (KS)
Candidiasis of bronchi, trachea, or lungs	Lymphoma, Burkitt's (or equivalent term)
Candidiasis, esophageal	Lymphoma, immunoblastic (or equivalent term)
Cervical cancer, invasive	Lymphoma, primary in brain (AIDS with negative HIV-antibody test if $< 60$ years of age)
Coccidioidomycosis, disseminated or extrapulmonary	<i>Mycobacterium avium</i> complex (MAC) or <i>M. kansasii</i> , disseminated or extrapulmonary
Cryptococcosis, extrapulmonary	<i>Mycobacterium tuberculosis</i> , any site (pulmonary or extrapulmonary)
Cryptosporidiosis, chronic intestinal ( $> 1$ month duration)	<i>Mycobacterium</i> , other species or unidentified species, disseminated or extrapulmonary
Cytomegalovirus (CMV) disease (other than liver, spleen or nodes)	<i>Pneumocystis carinii</i> pneumonia (PCP)
Cytomegalovirus (CMV) retinitis with loss of vision	Pneumonia, recurrent (more than one episode in a year)
HIV encephalopathy (HIV dementia)	Progressive multifocal leukoencephalopathy (PML)
Herpes simplex: chronic ulcers ( $> 1$ month duration); or bronchitis, pneumonitis or esophagitis	Salmonella septicemia, recurrent
Histoplasmosis, disseminated or extrapulmonary	Toxoplasmosis of the brain
Isoporiasis, chronic intestinal ( $> 1$ month duration)	Wasting syndrome due to HIV

The average time from an AIDS diagnosis until death has gradually lengthened for several reasons: there is an increased chance of early diagnosis through early testing; antiretroviral therapy has become more widely available and effective; and opportunistic diseases can be prevented, diagnosed, and treated more effectively.

### What is the immune system and how does HIV damage it?

The immune system is a collection of cells (e.g., CD4, CD8, macrophages) that act as the

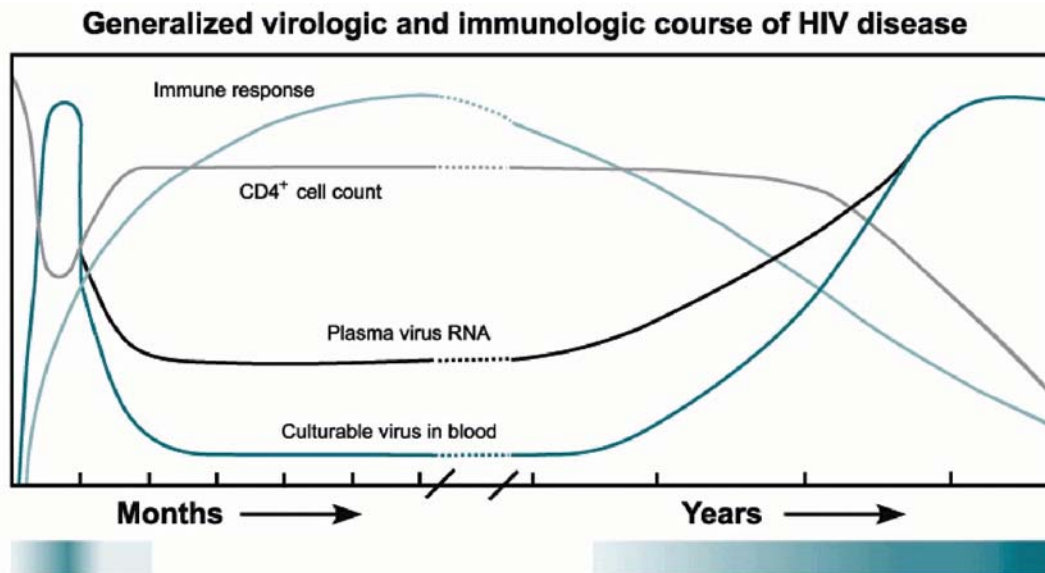
body's defense against invading organisms such as cancer cells, or infectious organisms (viruses, bacteria). When HIV enters the body, it multiplies rapidly and becomes present in large quantities in circulating blood. The high rate of viral activity, which is killing CD4 cells, triggers production of replacement CD4 cells and of HIV-specific antibodies. The production of antibodies is the immune response that causes the initial viral burden to drop. (See Figure 1)

Two to twelve weeks after becoming infected, many people will experience an acute retroviral syndrome with flu-like symptoms lasting two to three weeks. This is also referred to as seroconversion illness, or





Figure 1.



primary HIV infection and is the point at which large quantities of antibodies are being produced to attack the virus circulating in the blood. Due to the large quantity of virus circulating in the blood, early infection is one of the most contagious periods in HIV infection.

Because HIV can easily change parts of its genetic make-up, or mutate, as it replicates, it can escape attack by the body's defenses. When the immune system is damaged, it is less effective at protecting the body against illnesses and infections.

HIV can only survive and replicate inside a living cell. HIV infects the body through several different cells of the immune system, but immune dysfunction results primarily from the destruction of helper T cells, called CD4 + T lymphocytes. As more of these cells become infected, fewer are available to fight off disease. Diseases that a healthy immune system can prevent become more dangerous, and even life-threatening.

### How is HIV infection identified?

The body responds to HIV by producing antibodies to fight the infection. Therefore, the most commonly used method for determining if a person has HIV infection is to look for the presence of HIV-specific antibodies. Within 2 to 12 weeks of acquiring HIV, sufficient antibodies will be present to be detected in circulating blood.

Antibody tests may be done on blood from a blood draw (phlebotomy or a fingerstick), or with oral fluid (not saliva) collected via the OraSure® Test. The oral test uses a swab to absorb antibodies directly from the blood vessels in the mucous membranes of the lower cheek and gum. These are not tests for virus or AIDS.

Collected samples are tested for HIV antibodies using an ELISA (enzyme-linked immunosorbent assay), also referred to as "EIA". If this test comes back reactive, or positive, the test must be repeated. If two





positive ELISA test results are obtained, the result must be confirmed. The most commonly used confirmatory test is the Western Blot. Positive results should never be given to a person on the basis of the ELISA test only.

Through these standard procedures, it may take from 1-2 weeks to get test results. In November 2002 a new rapid test for HIV antibody was approved. It can detect HIV antibodies in fingerstick whole blood and provide results in 20 minutes or less. It has 99.6% sensitivity which means a positive result is very accurate, and 100% specificity, which means a negative result is very accurate, except during the “window period.” The rapid test still requires a follow-up confirmatory test.

The presence of antibodies indicates infection with HIV, though it does not determine the stage of HIV disease. There is also the possibility that a negative result can be falsely negative if testing was performed during the window period of infection.

### What is the “window period?”

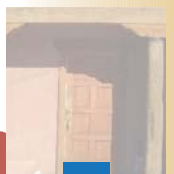
Testing for HIV is inconclusive if antibody production is not sufficient to register on the test. Even though a person is infected and capable of infecting others right after acquiring HIV infection, antibody production may take from two to twelve weeks in most people and up to six months in some. The window period is the time between becoming infected and producing enough antibody to register on the test. If a person is tested for HIV antibodies during this window, the test will come back negative. Timing of a risk exposure can be determined through an

interview. If it has been less than three months since a risk exposure, the person tested should be retested after at least three months from the risk exposure. It is important that patients understand the window period and take precautions not to infect others until a definitive diagnosis of infection can be made. A series of tests at baseline, 4 wks., 12 wks., and 6 months should be done after each risk exposure.

### What is the difference between confidential and anonymous HIV testing?

HIV antibody testing may be done in several different settings, including a physician's office, a designated testing center, or via a mobile service. If a person has a trusting relationship with a provider, they may be comfortable being tested by someone who knows their medical and social history. Others may prefer to be tested in a location where they are not known. Testing options vary from area to area. Colorado allows county health commissioners to determine if local health departments may offer confidential or anonymous testing. In most cases, HIV testing requires informed consent (implied in anonymous testing), and all persons being tested must be counseled both before being tested and when receiving test results.

In confidential testing programs, clients are asked to provide identifying information, including name and address. Using this information, it is possible to follow-up with people who do not return for test results and to offer counseling and intervention, such as assistance in contacting others who may have been exposed.





Anonymous testing does not require that individuals disclose identifying information. Records are kept by assigning code names or numbers that are matched to test results. Clients must remember the code to receive results, and it is not possible to follow up with persons who do not return for their test results. The test results are not traceable. No written documentation of the results is available to a third party.

Many sites offer both options. In Colorado, all test results are reported to the secure registry at the state health department for epidemic surveillance purposes. All test results are protected, with some rare exceptions, such as persons convicted of sexual crimes.

Confidentiality is more difficult to maintain if the test is billed to an insurance company. However, the Medical Information Bureau uses a generic "blood disorder" label in its national data bank, and unauthorized release of information is considered a breach of confidentiality.

### How is HIV transmitted?

Worldwide, studies have consistently documented that the three major means of HIV transmission are:

- contact with infected blood,
- unprotected sex with an infected partner, and
- perinatally from infected mother to infant

Infectious body fluids include:

- blood,
- semen,
- vaginal secretions,
- human breast milk (neonatal transmission), and
- any bodily fluid containing visible blood.

Although HIV has been detected in other fluids, unless there is also visible blood present, viral concentrations are not sufficient to transmit HIV. Among these fluids are tears, saliva, urine, feces, vomit, sputum, and nasal secretions. Sweat is not considered a risky fluid.

HIV is not transmitted by casual contact (shaking hands, hugging), coughing, sneezing, dry kissing, sharing food or utensils, sharing work space, donating blood, by insect bites or by animal bites.

**Blood-borne.** Blood-borne transmission may occur the following ways.

- Percutaneous exposure via sharing contaminated injection equipment, accidental needle sticks, tattooing, piercing.
  - ◆ All methods of injecting, into veins, muscles or under the skin, may transmit HIV. This risk increases as the number of persons who share equipment increases.
- An increasing proportion of IDU-related HIV infections in Colorado is among Hispanic males.
- The Denver metro area outreach study in 1996-2000 found an 83.6% prevalence amount Hispanic IDUs.
  - ◆ The risk of occupationally acquired HIV infection is low. Risk associated with a percutaneous exposure to contaminated blood is about 0.3%, compared to a 3-30% risk of acquiring Hepatitis. The risk of infection increases if a sharp injury is deep and injects blood, if there is visible blood on the device, and if the sharp was previously placed in a source patient's vein or artery.





- Receipt of contaminated blood, blood products or organs.
  - ◆ Due to screening, this risk is low; estimated by the American Red Cross as one in 800,000.
- Exposure through an open wound or mucous membrane
- Genital and oral STD lesions enable virus to enter the bloodstream and thus increase the chance of acquiring HIV infection through anal, vaginal or oral sex.

**Sexual.** HIV is primarily a sexually transmitted disease. Unprotected receptive anal intercourse is the greatest risk for both men and women. Anal intercourse between men remains the most common mode of HIV transmission among men of all racial and ethnic groups in Colorado. Transmission may occur to either partner during unprotected anal, vaginal or oral sexual intercourse. Transmission from male to female may be more efficient than transmission from female to male.

HIV is increasing more among women than among men, mostly due to infection through heterosexual contact. Women may be vulnerable to HIV for several reasons, including high risk behavior of their partners, substance use, poverty, violence, and financial dependence on men, which can undermine their ability to negotiate safer sex.

The HIV case rate is six times greater among Latinas than among non-Hispanic white women.

It is possible to get HIV through oral sex with a partner who has HIV. Blood, semen, and vaginal fluid containing HIV may enter cuts or open sores, or permeate mucous lining in and around the mouth.

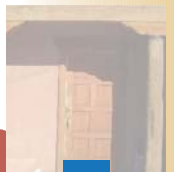
**Mother-to-child.** Without treatment, 20-30% of babies born to infected mothers will become infected. An infected mother can pass HIV to her child before, during, or after delivery. The greatest risk is during labor and delivery. After delivery, transmission risk is through breast milk. Factors that may affect the risk of vertical transmission include:

- mother's stage of illness, with greater risk in early infection and late disease,
- low CD4 count and high viral load,
- presence or absence of other STDs,
- breaks in the placental barrier,
- maternal drug or alcohol use,
- ruptured membrane more than four hours,
- duration of labor, including time in the birth canal, or
- Birth order in multiple births.

## Prevention Strategies for Infected Individuals

In the absence of a vaccine against HIV, prevention of initial infection is the most reliable method for stopping transmission of the virus. Prevention must also be discussed and supported with individuals who are living with HIV infection to assure they do not infect others. As outlined in the recent Serostatus Approach to Fighting the Epidemic (SAFE), prevention with positives includes five steps.

- Increase the number of HIV-infected persons who know their serostatus.
- Increase the use of health care and preventive services.





- Increase high-quality care and treatment.
- Increase adherence to therapy by individuals with HIV.
- Increase the number of individuals with HIV who adopt and sustain HIV/STD risk reduction behavior.

It is important to make people aware of risks for infecting others or for superinfection acquiring additional strains of HIV infection, and to encourage use of prevention and care services. HIV transmission prevention strategies (in descending order of effectiveness) include:

#### Blood contact:

##### IDU

- Avoid injection drug use.
- Avoid sharing equipment with others.
- Clean equipment with bleach and water between users.

##### Other percutaneous

- Occupational Exposure
  - ◆ Avoid performing invasive procedures, handling sharps.
  - ◆ Follow universal precautions.
  - ◆ Treat exposures immediately following post exposure guidelines.
  - ◆ Become familiar with policies for infected employees.
- Tattooing and Piercing
  - ◆ Choose vendors that use sterile needles and other equipment (including ink) for each customer.

Blood, blood products, donated tissues, organs

- Do not donate blood, organs or tissue, including sperm for artificial insemination.
- Do not share toothbrushes, razors, or other personal items that may contain blood or body secretions.

#### Sexual transmission:

- Practice sexual abstinence.
- Learn the HIV status of sexual partners.
- Practice safer, protected sex.
- Use latex condoms properly for each sexual encounter.
- Use barriers for oral sex.
- Note: safer sex does not eliminate all risks
- Avoid sex with HIV-infected individuals or those at high risk for HIV infection.
- Avoid sexual practices, such as anal sex, that may damage body tissue.
- Practice sexual behaviors that do not include sharing body secretions, such as:
  - ◆ body massage,
  - ◆ closed-mouth kissing,
  - ◆ hugging, and/or
  - ◆ mutual masturbation.

#### Mother-to-Child

- Avoid childbearing.
- If interested in conception, discuss with primary care provider the factors that influence risk of perinatal transmission.
- Follow antiretroviral treatment guidelines to prevent perinatal transmission.
- Learn about other prevention methods, such as sperm washing.
- Deliver via Cesarean section.





## Secondary Prevention

Another aspect of prevention for HIV-infected patients is slowing or stopping progression of illness, or reducing morbidity (illness) and mortality (death). This is sometimes referred to as secondary prevention, and focuses on early detection of HIV infection and appropriate treatment of HIV, as well as prevention or proper treatment of opportunistic infections. Identifying patients at an early stage of infection may help to decrease the severity of illness.

Common interventions at the secondary prevention level include screening and education about symptom recognition and slowing disease progression.

## Risk Reduction

It is not always realistic to expect an individual to follow immediately the most effective transmission prevention strategy. For example, someone with a drug addiction may not be able to discontinue drug use right away, but may be willing to learn a method other than injection, or to refrain from sharing equipment, or to learn equipment cleaning procedures. It is, therefore, important to help people realistically evaluate their risk for exposing others to HIV and to help develop a strategy that will reduce this risk, and ultimately achieve the most effective method. The strategy should be tailored to the behaviors, circumstances and special needs of the infected person. By setting realistic goals that can be achieved, the client is not set up to fail. This is generally a two-step process.

## Patient-centered risk assessment

- Through discussion, the counselor or care provider helps the patient assess and acknowledge his/her risk for acquiring or transmitting HIV infection.
- Assessment is an interactive process, not just responses to a checklist.
- It should be done in an empathetic way, with special attention to the unique and ongoing behaviors and circumstances (e.g., sexual or drug use practices, STD history) that have and may continue to place the client at risk for HIV infection/transmission.

## Personal risk reduction plan

Based on the risk assessment, a plan should:

- be based on client-identified, successful and unsuccessful, previous attempts to prevent risky behavior,
- be consistent with client's desires to change risky behavior, and
- should be negotiated based on client's personal circumstances.

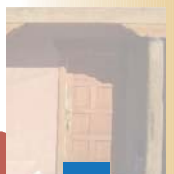




Table 2.

Secondary Prevention Measures for HIV-infected Persons

- Follow primary prevention measures.
- Protect partners from body secretions during sexual activity.
- Refrain from donating tissue or blood.
- Seek professional help to terminate drug use, if applicable.
- Refrain from sharing drug equipment if unwilling to stop drug use.
- Seek early treatment for HIV infection.
- Inform primary medical provider of HIV status.
- Notify former and current sexual partners so they can be tested for HIV.
- Clean spilled blood or body secretions with 1:10 diluted bleach in water.
- Avoid pregnancy, or follow HIV treatment protocols for self and infant.
- Inform health care workers on a need-to-know basis only, to maintain confidentiality.
- Follow good health practices, such as exercise, nutrition, no substances (alcohol, nicotine).

## HIV and MAJOR CO-MORBIDITIES

### Substance Use

Exposure to HIV-infected blood through the sharing of needles in injection drug use is one of the most common causes of HIV transmission in the U.S. today. It is difficult to know exactly how many people use/administer drugs through injection. Based on a 1995 Colorado study, there were between 15,000 and 18,000 IDUs in the state. It is assumed that the number has increased. Directly or indirectly, IDU is the greatest risk factor for HIV among women and children. IDU is a relatively greater risk factor in rural areas. Not all injected drugs are illicit. Other injected substances include prescription medications, steroids and vitamins.

Non-injectable recreational drug use can also lead to HIV risk behaviors. Crack is a form of cocaine that usually is smoked. Use

of crack and other recreational drugs may increase risk by lowering inhibitions and impairing judgement, thus making users less likely to negotiate or practice safer sex. To obtain drugs, individuals will often exchange sex for the drugs.

Along with recreational drugs, alcohol is known to have a disinhibiting effect, even in small amounts. Alcohol can impair fine motor coordination and judgment. Alcohol use can lead to persons being less likely to make the "right" decisions when it comes to using condoms or negotiating safer sex, putting them at increased risk for HIV infection.

### Hepatitis C Infection (HCV)

Hepatitis C (HCV) is a virus that causes chronic liver infection. HCV is found in up to 80 % of people with HIV who have ever injected drugs. In Colorado, 15.3% of all HIV/AIDS cases are co-infected with





Hepatitis C. It has been suggested that people co-infected with HIV and HCV have a more rapid progression to liver disease.

HCV infection may also impact the course and management of HIV infection. The latest U.S. Public Health Service/ Infectious Diseases Society of America (USPHS) guidelines recommend that all HIV-infected persons should be screened for HCV infection.

### Sexually Transmitted Diseases (STDs)

Studies conducted by the CDC indicate that individuals who are infected with STDs are at least two to five times more likely than uninfected individuals to acquire HIV if they are exposed to the virus through sexual contact. In addition, if an HIV-infected individual is also infected with another STD, that person is more likely to transmit HIV through sexual contact than other HIV-infected persons. There is substantial biological evidence demonstrating that the presence of other STDs increases the likelihood of both transmitting and acquiring HIV.

When an individual is infected with an STD, he or she becomes more susceptible due to breakage of the skin e.g. genital ulcers seen with syphilis, herpes or chancroid. These sores then create a portal entry for infection to occur. Non-ulcerative STDs (e.g. chlamydia, gonorrhea, and trichomoniasis) increase the concentration of cells in genital secretions that can serve as targets for HIV.

HIV infected individuals co-infected with STDs are more than twice as likely to shed HIV in their genital secretions. For example, men who are infected with both gonorrhea and HIV are more than twice as likely to

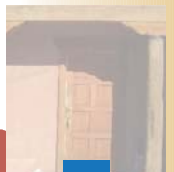
shed HIV in their genital secretions than are those who are infected only with HIV. Moreover, the medium concentration of HIV in semen is as much as ten times as higher in men who are infected with both gonorrhea and HIV.

### Mental Health Issues

HIV can cause severe mental and emotional problems in two ways. The first is a reactive depression to the diagnosis itself. Second is that HIV does enter the central nervous system and can cause organic brain syndromes with a host of different mental and emotional symptoms, with depression being one of the most common. Whereas earlier developed antiretroviral medications do not cross the blood brain barrier, newer drugs do cross into the central nervous system and may help reduce the effect of HIV on person's mood and thought process. It is imperative to assess for emotional problems and to refer to a psychiatrist when necessary.

Numerous anti-depressant and anti-anxiety medications when correctly prescribed and taken as prescribed can also fight the symptoms of HIV related mental and emotional illness. However, caution must be used as there are drug-drug interactions between antiretrovirals and many mental health medications.

The provider should also be aware of a person's emotional stability in relation to issues such as medication adherence, substance abuse, and transmission issues.





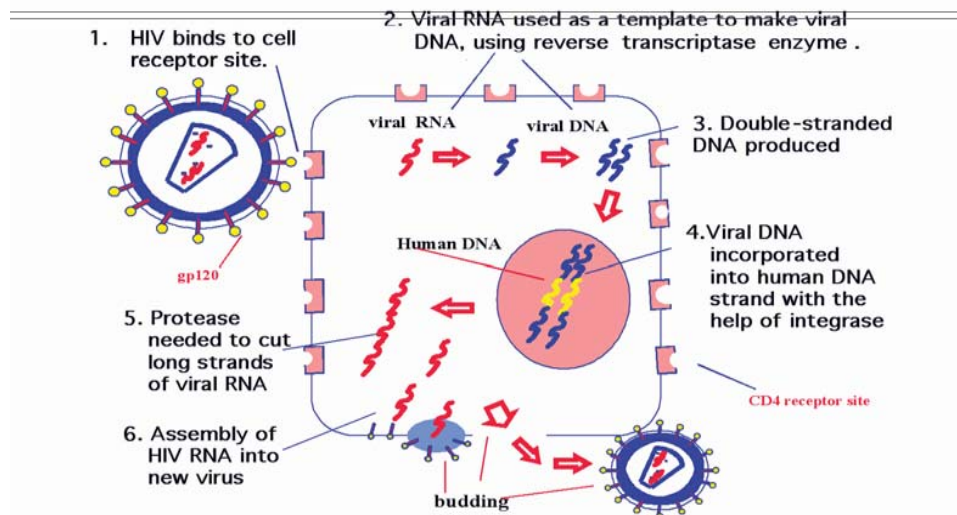
## HIV/AIDS TREATMENT

### How do HIV drugs work?

Drugs used to treat HIV infection do not kill the virus, but they do slow down its ability to reproduce, or multiply (replication). This slowed production of virus allows the immune system to produce new cells that work to slow down disease progression, the presentation or recurrence of opportunistic infections.

HIV drugs generally fall into four classes, categorized by how they affect HIV.

- **NRTIs** - nucleoside/nucleotide analogue reverse transcriptase inhibitors; "nukes"
  - ◆ These were the first anti-HIV drugs developed. They block an HIV enzyme called reverse transcriptase, which is necessary to convert viral RNA from the virus into viral DNA using the host's genetic material. This is an early step in viral replication. Drugs in this class include abacavir/Ziagen, didanosine/ddi, lamivudine/3TC, stavudine/d4T, zalcitabine/ddC, zidovudine/AZT, combivir (AZT + 3TC), trizivir (AZT + 3TC + abacavir), and tenofovir (the nucleotide).
- **NNRTIs** - non-nucleoside reverse transcriptase inhibitors; "non-nukes"
  - ◆ These drugs also inhibit replication of HIV by blocking the reverse transcriptase enzyme through a slightly different mechanism. Drugs in this class include delavirdine/DLV, efavirenz/EFV, and nevirapine/NVP.
- **PIs** - protease inhibitors
  - ◆ These drugs block the action of the protease enzyme that cuts protein sections necessary to assemble new virus copies before they rupture from the infected immune cell. Drugs in this class include indinavir/Crixivan, ritonavir/Norvir, nelfinavir/Viracept, saquinavir/Invirase or Fortovase, and amprenavir/Agenerase, and lopinavir/Kaletra .
- Entry or fusion inhibitors
  - ◆ Fusion inhibitors are a fourth class under development. These drugs prevent HIV from entering healthy cells. The only FDA approved drug in this class is enfuvirtide/Fuzeon, for use in ART combinations to treat advanced HIV.





## What is combination therapy?

Combination therapy for HIV/AIDS, often called highly active antiretroviral therapy (HAART), is the recommended treatment for HIV infection. This therapy involves prescribing 3 or more antiretroviral drugs in combinations that typically draw from two or more classes of medications to broaden the impact of the drugs against the virus. For most people, HAART slows progression of HIV disease, slows development of resistance, and enables the immune system to rebound. The combinations vary from patient to patient. Individualized regimens are based on many factors, including treatment history, resistance patterns, side effect tolerability, lifestyle, daily or travel schedule, living situation, probability of successful adherence, and other non-HIV medications. Monotherapy should never be prescribed. A two drug regimen is also unlikely to be effective, and may be detrimental, leading to resistance.

Following directions for taking HIV medications is very important (also see section on adherence). The goal of drug therapy is to reduce the amount of HIV in the blood to as low as possible. If medications are not taken properly, the drug will become ineffective in preventing HIV replication. This is development of drug resistance, which allows HIV to again destroy immune system cells, thereby reducing the body's ability to fight off opportunistic infections. Since most drugs in the same class are similar to one another resistance to one may cause resistance to other drugs in the same class. Thus, developing resistance may cause loss of treatment options.

Persons with a lower viral load are less likely to progress from HIV to AIDS. The levels of the antiviral drugs must be high enough to keep HIV from making copies of itself.

When a drug dose is missed, HIV can start replicating because the level of drug in the body drops. Some drugs stay in the body longer than others. This is why different medications are taken at different times. Sometimes, whether medications are taken with or without food can affect how well they work.

## What tests are used to monitor HIV treatment effectiveness?

**CD4 counts**, or T-cell assays, measure the number of immune system CD4 T cells circulating in peripheral blood by counting the number in a standard quantity, a cubic millimeter (mm<sup>3</sup>), of blood. CD4 counts are a good indicator of how the immune system is functioning, and disease progression follows a fairly predictable pattern that can be related to CD4 counts. A "normal" CD4 + cell count is in the range of 800 to 1200. Persons infected with HIV can have lower readings. A CD4 count is one factor considered when deciding whether to initiate antiretroviral treatment or prophylaxis for opportunistic infections.

**Viral load test** - Viral load measures the number of ribonucleic acid (RNA) strands of HIV in the plasma or serum of an HIV-infected person. Viral load measures are an indication of how active the virus is in the system and how fast disease is progressing. Measuring viral load helps make treatment decisions easier at all stages of HIV disease, especially during asymptomatic periods when the CD4 T-cell count is close to normal.





Viral loads are generally highest during initial infection and again in advanced disease. Viral load tests may also serve as an indicator of successful treatment. If a patient begins a new therapy and viral loads decrease at least by half of the previous amount, then the new therapy is considered effective. Patients with an "undetectable" viral load still have virus in their bloodstream, but the test is not sensitive enough to identify it below a certain concentration. People with "undetectable" viral loads may still transmit virus, though the risk is less than when viral loads are higher.

**Resistance testing** is used to determine whether the virus is still susceptible to drugs. There are two general categories of resistance testing.

**Genotyping** - This test conducts genetic analysis of the virus to detect and identify mutations associated with drug resistance in a person using anti-HIV drugs. In measuring antiretroviral drug resistance it is possible to distinguish between actual resistance to the drugs that occur in people who do not take the drugs as prescribed, do not absorb the drugs well or do not metabolize them very quickly. The results of the test can help physicians prescribe the most effective antiviral drug regimen for each patient.

**Phenotypic testing** - This test measures the amount of drug needed to completely stop HIV replication in a blood sample.

### When should HIV treatment start?

A treatment plan should be decided between a physician with HIV expertise and a well-

informed patient. Treatment should begin when the patient feels well-informed, ready, in agreement with the doctor about what the type of treatment should be, and when he or she believes the treatment will be successful. Considerations in initiating treatment may include: CD4 counts, viral load, medications available, general health, an evaluation of factors that may influence adherence, current science, and tolerance of side effects.

Treatment of acute primary HIV infection is generally recommended, regardless of a patient's CD4 + or viral load levels or whether the patient is experiencing symptoms. Early treatment helps slow virus replication, decreases the likelihood of viral mutation, and helps preserve the immune system. Side effects of the medications are a consideration in beginning treatment during acute infection.

Some patients choose to wait until CD4 + levels drop to a certain level (below 500 or 350 or even 200), and/or viral loads increase beyond undetectable or by a certain amount over a low point (such as a tenfold increase from 1,000 to 10,000), or when a patient develops symptoms. The decision when to start any treatment should be made in consultation with the patient's primary care provider, based on the most current research findings. The patient's right to informed consent must be respected in all treatment decisions.

### What are the side effects of ART?

Many of the drugs prescribed for HIV infection have side effects. They are known based on the experience of people who took the drug during its clinical trials, and on the





experience of everyone who took the drug once it was on the market. These reactions are often dose-related; lowering the dose may relieve the symptoms but switching drugs is a more likely response.

Side effects may include nausea, vomiting, diarrhea, reduced appetite, insomnia, headache, abnormal liver function, peripheral neuropathy, pancreatitis, dry mouth, rash, seizures, anemia, muscle pain, neutropenia, bone marrow depression, and GI intolerance. They can show up after one dose, or after one to two weeks, or after months on a drug. Often the side effects will resolve after a person's system adjusts to taking the medication.

Some patients may also experience changes in lipid metabolism that results in redistribution of body fat and elevated cholesterol counts. It is still not clear whether these events are related to the HIV drugs or to having HIV itself.

Anyone experiencing side effects should see their physician to figure out what is causing them and what to do about it. Drugs should never be stopped without consultation with a doctor. If tolerated, HAART can improve the overall health and quality of life for many patients.

### What is adherence and why is it Important?

Adherence refers to how well a patient is able to follow the treatment plan developed with his/her primary care provider. The aspects crucial to the treatment plan include: taking the correct dosage at the correct time, storing the medications properly, and keeping

medical appointments for follow up testing and evaluation.

A certain amount, dose, of drug is necessary to sustain low rates of viral reproduction. Skipped or incorrectly taken drug doses can cause drug levels in the body to drop. The virus can then begin to multiply more quickly, even with the lowered amounts of drug still in the body. This leads to resistance, which means the virus learns to ignore the drugs and reproduce in their presence. Once resistance occurs, it is difficult and sometimes impossible to reverse it. That means the particular drug, and often other drugs in the same class, will no longer be able to fight HIV in the person who has developed resistance. This is crucial because of the limited options clients have regarding prescribed medications.

Some of the key factors influencing adherence are:

- active alcohol/drug use
- economic issues such as homelessness and unemployment
- work schedule
- childcare and travel
- mental health issues: depression, schizophrenia, cognitive impairment
- drug therapy: doses, cost, eating requirements, side effects such as vomiting
- inconsistent access to care: migrant workers, incarceration
- lack of knowledge about disease and medication
- concerns about taking medication
- clinician-patient relationships
- personal beliefs about the value of the treatment
- confidentiality





Strategies to improve adherence include:

- care providers taking time to explain treatment plan and benefits
- being patient and supportive with clients
- involving the patient in treatment plan
- taking good history
- addressing any psycho-social barriers to adherence
- monitoring adherence by asking effective questions
- utilizing other agencies and service providers
- being accessible to clients
- utilizing family support system.

### What are some other treatment considerations?

An HIV positive patient should not receive vaccines that contain live virus or bacteria (oral polio, bacilli Calmette-Guerin, oral typhoid, varicella zoster).

Nonliving or nonbacterial vaccines can be administered based on the risk of disease and the effectiveness of the vaccine. According to the Centers for Disease and Control and Prevention, HIV patients should receive influenza virus, Pneumoniae (pneumoniae polysaccharide) Hepatitis B, inactivated polio and tetanus vaccines if not up to date.

Asymptomatic HIV positive patients should have a follow-up visit every 3 to 6 months. The visit may include a physical exam, several lab tests to monitor drug effectiveness and general well-being, and review of any factors affecting ability to adhere to medical regimens. Some tests should be done every year, such as TB skin test. Women should receive a pap test every six months. VDRL for sexually active patients should be done as needed.

### What is complementary therapy?

Complementary therapy has become integral to treatment of HIV and AIDS. Many people with HIV infection believe that such treatments as special diets, Chinese herbs, and vitamin preparations will help control HIV infection. The effectiveness of these treatments has not been tested in clinical trials.

Most standard medications treat HIV directly, attacking the pathogens in the body. By contrast, complementary therapies seek to treat the individual holistically, building up the person's strength (including the immune system). Examples of common complementary therapies for HIV/AIDS include: acupuncture, aromatherapy, biofeedback, herbal medicine, meditation, nutrition, yoga, or physical exercise

### Treating Opportunistic Infections

By the time people with HIV develop AIDS, their immune systems are usually severely damaged. People with HIV may suffer from a variety of infections caused by certain fungi, parasites, viruses, and bacteria. People with AIDS can have more than one infection at a time. Doctors now can treat or even prevent many of these infections. Infections or conditions diagnosed in people with HIV disease include:

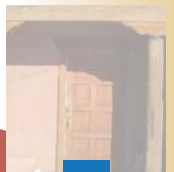
- *Pneumocystis carinii* pneumonia (PCP) accounts for the largest number of opportunistic infections even though it is preventable.
- Chronic herpes, sores that heal very slowly, found especially on the genitals and anus and in the mouth





- Candidiasis, including vaginal "yeast" and thrush, which causes white patches in the mouth that can extend down the throat and into the esophagus
- Cytomegalovirus infection, most commonly found in the eye, gastrointestinal system, and central nervous system
- Tuberculosis (TB), an infection of the lungs and sometimes other organs, caused by mycobacteria
- *Mycobacterium avium* complex (MAC), caused by mycobacteria that resemble TB, MAC appears in people whose immune systems are badly damaged, and causes fever, weight loss, weakness, and sometimes diarrhea
- Recurrent pneumonia, a bacterial lung infection causing fever, shortness of breath, and a productive cough
- Cryptococcosis, a fungal infection that can cause pneumonia or meningitis and inflammation of the brain
- AIDS dementia complex (HIV encephalopathy), is the most common neurological disorder associated with HIV; severity depends on extent of central nervous system damage
- HIV-AIDS wasting syndrome, severe anorexia and cachexia that prove resistant to weight-gaining efforts.

Some of these infections can appear in people with healthy immune systems. When they appear in people with HIV infection (or in those whose immune systems are suppressed by medication), however, these infections tend to be more severe, more widespread, and more difficult to treat.





## PROVIDING CULTURALLY GUIDED CARE AND TEACHING ADVOCACY

### Objectives

Upon completing the Culturally Guided Care and Advocacy section, learners will be able to:

- Define advocacy
- Recognize cultural issues that may influence client services
- Identify opportunities for teaching advocacy
- List some resources for HIV-infected clients

### What is Advocacy?

Advocacy is acting in the interest of, or to support or benefit another. An advocate works with a client, assisting him or her in accessing helpful services and systems of care. Advocacy is important because it models behaviors that allow the client to become informed, to identify and evaluate resources, and to learn how to ask questions regarding their health care options. Anyone can be an advocate; a client, health care worker, or family member. Advocacy is an evolving, shared process, with the ultimate goal of empowering the client to become his/her own advocate, effectively negotiating the health care system, and thus, allowing the client to live with the decisions they make.

In this section, case studies will illustrate cultural considerations in working with clients, opportunities for teaching self-advocacy in those cases, and potential resources that may assist clients in managing their HIV infection.

### CARLOS

#### I. Case Study

Carlos is a 27- year old Latino who appears healthy. He is the youngest of four children, the only male, second generation. He is non-gay identified and has sex with men. He has a history of incarceration and recently has been released from the local county jail. Currently, he is homeless. He is HIV positive, is not receiving any medical services and is not taking HIV medications. Carlos feels isolated because there is no one he trusts, and he feels that his HIV status is just one more thing to worry about. Carlos does have family living in the area. He reports being closest to his mother and youngest sister and feels estranged from his father. He has never disclosed his sexual behaviors with his family due to feelings of shame and guilt.

#### II. What are the cultural issues or values that may influence how you intervene?

*Machismo* – in Latino culture men are expected to be rational, profound, strong, authoritarian, independent, and brave.

Carlos may feel that he needs to shoulder his situation alone, to be brave and strong and not depend on others. His clinician or other provider should acknowledge and demonstrate understanding of Carlos' choice to withhold information from his family and others. Through supportive conversation, one may be able to help Carlos identify a family member to whom he can disclose, and





demonstrate his strength in the face of his diagnosis. A possible future niche for Carlos may be as an advocate for others with HIV infection, which would enable him to lend the benefit of his experience negotiating systems of care to others with less experience. This would put him in a leadership position.

**Sexuality** -in Latino culture sex is generally not discussed as influenced by Catholicism.

Carlos does not feel comfortable talking to his family about sex since "sexuality" was never discussed openly in his family. In addition, Carlos experiences shame and guilt regarding some of his behaviors. Thus, his clinician or other provider must be non-judgmental in interviewing Carlos about risk factors, and may actually want to begin by learning from him how he's doing, and what he knows about his condition (last CD4 count, viral load etc.), before exploring sexual behaviors for transmitting HIV.

**Cultural Fatalism** -this may include a belief that negative events such as illness are God's way of testing an individual.

Carlos may feel that his HIV infection is just one more thing to worry about. As a consequence he has not sought out medical services for his HIV infection. The clinician or other provider can begin by exploring with Carlos how much he knows about treatment options. After exploring Carlos' views regarding medicine the provider can offer referrals to appropriate service providers. This will help Carlos learn that systems of care exist to meet his needs and will meet him where he's at. Carlos may begin by seeing a non-western specialist (curandera or herbologist). This may encourage him later to seek out traditional HIV therapy and counter his feelings of cultural fatalism.

**Confianza** -showing personal interest in Latino individuals helps win their trust.

Due to his life experiences Carlos does not trust easily. He is ambivalent about disclosing any personal information. Through supportive conversation the clinician or provider can begin by showing interest in Carlos by engaging in conversations that initially are non-personal and non-threatening. As trust develops Carlos may feel more comfortable disclosing what is important to him. The provider is illustrating skills that Carlos can use in his interpersonal relationships with his family and health care providers.

### III. What are the opportunities for teaching advocacy?

**Machismo** – Explore with Carlos the importance of his family, i.e., what his role in the family is as the only son, what is expected of him, and how his sense of machismo can be a source of strength.

The clinician or other provider can begin one-on-one supportive counseling. These sessions can focus on Carlos' definition of *Machismo*, what it means to him, i.e., protector of and provider for the family. The provider can explore with Carlos how he can see his *Machismo* as strength, for example, he can teach his younger family members what they can do to protect themselves from getting infected. This may help Carlos "reintegrate" into the family so that he recognizes them as a source of support and strength.

**Sexuality** – Explore how his sexual behaviors and lifestyle affect his sense of *machismo*. Are they in conflict? If so, what are the





consequences?

Initial discussion between Carlos and his clinician may focus on his HIV status, building trust to a point that he can comfortably discuss his sexual behaviors and lifestyle. The provider can then discuss how his lifestyle conflicts with his sense of *Machismo*, i.e. were there any verbal or non-verbal messages from the family about his duty or role as the only son? The provider can help Carlos recognize a balance between accepting his lifestyle while also being a source of strength in the family.

*Cultural Fatalism* – Explore how HIV medications could be helpful. Support his non-western beliefs such as his visits to a *Curandera*. Explore how he can gain more control in his life.

The clinician or other provider can begin by asking Carlos about his past treatment history, including his experience of the medical system. The provider can ask Carlos what has worked in the past. Building on this information, the provider can refer Carlos to a medical provider with whom he will feel comfortable. This may mean taking Carlos to his first appointment and being there for support. As time progresses, Carlos may gain enough self-confidence to become his own advocate and gain control.

*Confianza* – Slowly establish rapport with Carlos. Show personal interest and establish realistic goals.

It is important to slowly build rapport with Carlos since he has learned over time not to confide in or trust others. The clinician or other provider can begin by showing personal interest, asking him what his needs are, what is important to him, and what services would be most helpful to him now. The provider needs to be realistic when discussing Carlos' needs. It will be important for the provider to establish goals that Carlos can meet so as not to set him up for failure.

## IV. Resources

- AIDS Service Agency
  - ◆ Case Management or Advocacy
  - ◆ Peer Support Group
- Department of Social Services
- Social Security Administration
- Housing Authority
- Community Health Center
- AIDS Drug Assistance Program (ADAP)

## THERESA

### I. Case Study

Theresa is a 35-year old Latina, single mother of two children. Mario is eleven years old and Juanita is thirteen years old. Theresa has been divorced for the past eight years. She is second generation, the middle of three children. She has a long history of respiratory problems, and has just been hospitalized for this condition. While hospitalized, several tests are conducted and she tested positive for HIV disease. Her doctor has told her and her family that she has AIDS. She has no history of substance use. Theresa fears that she will not live long enough to care for her children. Theresa's oldest sister is caring for her children while her parents and younger brother are at the hospital for support.

### II. What are the cultural issues or values that may influence how you intervene?

*Familismo*– The importance of the family system should always be acknowledged. Family ties create strong feeling of loyalty and solidarity and provide a solid support system.





Theresa's family has been at the hospital for support. Her oldest sister is taking care of Theresa's children. Her clinician or other health care provider should acknowledge the importance of Theresa's family support system. The clinician or other health care provider may suggest ways that the family could work together to further support Theresa. For example, the family may meet with the Infectious Disease doctor so that they can become more knowledgeable about HIV disease. By becoming educated the family can extend support to Theresa. With the support of her family Theresa can now focus on her own needs and become her own advocate.

*Personalismo* – Latinos tend to stress the importance of personal rather than institutional relationships. Latinos expect those with whom they interact to be warm, friendly, personal, and to take an active interest in their personal lives.

Theresa's health care provider has included her family in her care. The provider has made a point to greet and acknowledge all the family members. Family members may be asked how they are dealing with the crisis and what they need in order to better cope with the situation. This could be education, support, and referrals. By engaging the family the provider increases the likelihood that the family becomes involved in Theresa's health care.

*Death and Dying* -Latinos generally view death and dying as another step in the cycle of life and are able to talk about the subject without fear and denial.

Theresa has voiced her concerns that she will not live long enough to care for her children. It is of great importance that the clinician or other health care provider discuss

with Theresa her prognosis, what to expect, and more importantly address what she can do now to ensure the future of her children. For example, the provider may discuss the importance of a living will and medical power of attorney. By addressing these issues Theresa may feel more at ease and inclined to focus on her medical needs.

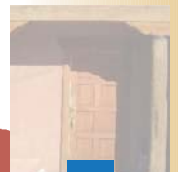
### III. What are the opportunities for teaching advocacy?

*Familismo* – Explore how the family system can work together to support Theresa and her children. Educate the family system about HIV disease.

Theresa and her family may all be experiencing "shock" and "disbelief" that she has AIDS. It is imperative that the clinician or other provider help the family understand what an AIDS diagnosis means. The provider can offer suggestions on how the family can support each other through this crisis. This relieves Theresa of having to bear this burden alone. The family becomes a strong ally and Theresa is allowed to focus on what she can do to improve her health.

*Personalismo* – Develop rapport with Theresa by incorporating her support system, acknowledging her concern for her children, and spending time getting to know who she is.

Theresa expressed concern that she may not be able to care for her children. Her clinician or other provider should invite her to explore her concerns. This process may take time to develop. Be willing to make home visits, share a meal, and to show interest in the family. As a result of the interaction with her provider Theresa may be





able to face her fears and become proactive. For example, Theresa may want to discuss treatment options.

**Death and Dying** – Support Theresa's cultural acceptance of death and dying. While Theresa is still healthy discuss who will make health care decisions and who will take guardianship of the children.

Relying on Theresa's openness to discuss death and dying, explore her concerns about her health as well as feelings about the future of her children. Through supportive one on one counseling the clinician or other health care provider can "coach" Theresa on approaching her family about the interim care of her children and guardianship. By

discussing these priorities with her family Theresa may feel a sense of peace in knowing that her children will be cared for.

#### IV. Resources

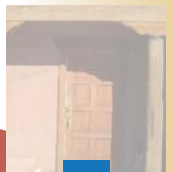
- AIDS Service Organization
- Department of Social Services
- Social Security Administration
- Community Health Center
- Support group
- AIDS Drug Assistance Program (ADAP)
- Legal Aid
- Caregiver Support
- Home Health Care





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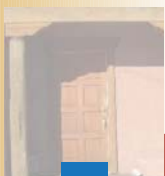
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## Appendices





## Appendix 1

### Trainer Resources

### Tips for Trainers

Take advantage of the opportunity to learn during your own training. Put yourself in a trainers shoes, try to anticipate the questions you may be asked, and ask them in the safe environment of your training preparation.

*You don't have to know everything!* In fact, you won't, and probably couldn't reach that goal. Be thoughtful in your responses, and give yourself permission not to know something. You may offer to find another resource person, do some research and get back to someone with an answer, or refer a trainee to a source such as an Internet site or a specialized program or agency.

If you give a personal opinion, be respectful and be sure to acknowledge that it is your personal opinion or experience.

Do as much additional reading and research as possible beyond the curriculum prior to conducting a training. The curriculum bibliography is a good starting point. Learn something about the population and cultural characteristics of the community in which your trainees will be working, and focus your additional learning on an enhanced understanding of the unique qualities of that population, i.e., are they recent immigrants? from where? what is the predominant language? how do they

identify? does the family have a long history as US citizens? how do they support themselves? what religious/spiritual practices sustain and comfort them? and so forth.

Explore your trainees understanding of the characteristics of the local community/service area, and incorporate their information in your training.

When presenting statistics, be aware of how, when and from whom they were collected, as they could be misrepresentative. For example, it is unwise to generalize to a large population based on data collected from or a response made by a small group of people. Data collected through an interpreter may not be as reliably recorded as data collected directly in someone's preferred language. Or, data collected over a very long period of time and reported cumulatively may not provide an accurate picture of the present condition (e.g., AIDS cases were reported less by Latinos in the early years of the epidemic. Thus, percentages and comparisons to other populations based on all years may not be as good an indication of the impact of HIV in the Latino community as data from recent years only).





## Cultural Awareness Exercise: Recognizing One's Biases

(Adapted from Campinha-Bacote, 1994)

### I. Materials/Equipment

six to eight portable chairs  
six to eight volunteers

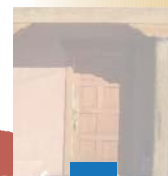
### II. Introduction

Based on Campinha-Bacote's (1991) Model of Cultural Competence, explain to the participants the construct of cultural awareness\*. Inform the participants that they will be engaging in an experiential exercise that will allow them to work together to explore their assumptions and perceptions.

- Cultural awareness is the deliberate, cognitive process in which the healthcare provider becomes appreciative and sensitive to the values, beliefs, lifeways, practices and problem-solving strategies of a client's culture. This awareness process must involve: 1) a self-examination of one's own assumptions about and biases towards other cultures; and 2) an in depth exploration of one's own cultural background. The stages of cultural awareness are:
  - unconscious incompetence - not being aware of lack of cultural knowledge
  - conscious incompetence - being aware of lack of knowledge about another culture
  - conscious competence - conscious act of learning about another's culture, verifying generalizations and providing culturally relevant interventions
  - unconscious competence - the ability to automatically provide culturally congruent interventions to persons from diverse cultures

### III. Instructions

- Solicit at least 6 volunteers from the audience (no more than 8). There must be at least two males and two females.
- Designate two of the volunteers as the "Cultural Experts (CE)." One CE must be male and one must be female. The remaining volunteers will be the "Mystery Culture (MC)." There must be at least one male and one female MC volunteer.
- Arrange an interview setting in which the cultural experts face the mystery culture members.
- Inform the cultural experts that across from them sit members of a culture unfamiliar to them. The CE goal, as a team, is to identify three rules or behaviors that govern the unfamiliar, or mystery culture. (You may want to give examples to clarify the goal, e.g., "a rule may be that all MC members cross their legs, or that they speak loudly.) Be sure the cultural experts know that their goal is to reveal patterns in the MC responses, not to identify specific ethnic, cultural or religious groups.)
- Ask the cultural experts to leave the room while you inform the audience and the mystery culture volunteers what three rules they should follow. They are:
  - MC members may only speak to persons of the same sex, i.e., men may only respond to men and women may only respond to women.
  - MC members may only reply with a "yes" or "no" answer, regardless of the question asked by the cultural experts.





- A “yes” or “no” response is solely based on whether the cultural expert smiles or not when communicating with a member of the mystery culture. Specifically, if a cultural expert smiles during communication with an individual of the same sex, the MC member should respond with a “yes;” if the cultural expert does not smile, the response should be “no.”
- To assure that the mystery culture members understand the rules, facilitate a brief practice before inviting the cultural experts to rejoin the group. Because these cultural “rules” are not likely to be practiced by the volunteers, it may be easy to make errors. Common errors might be:
  - Unintentionally responding to a person of the opposite sex. If questioned by someone of the opposite sex, either sit quietly and maintain eye contact, or look away, but DO NOT speak to the cultural expert.
  - Responding with an answer other than “yes” or “no.” For example, one might answer the question “what is your name?” almost automatically. However, the mystery culture “rule-based” response in that case would be to say “yes” if the questioner was the same sex and smiled while asking the question, and “no” if the questioner was the same sex but did not smile, and silence if the questioner was the opposite sex, even if he/she smiled.
- Once the rules are explained, understood and practiced, invite the cultural experts back into the room. Remind them that their goal is to identify three “rules” that operate in the mystery culture. Instruct

the cultural experts to ask questions of individual members of the mystery culture, rather than addressing questions to the entire group. Further, instruct the CEs to work as a team, and to inform the facilitator when they believe they have identified a rule. The facilitator will tell the cultural experts if they have identified a rule correctly.

- Limit the interview segment of the exercise to 15 minutes, regardless of whether or not the cultural experts have identified all three rules.
- At the end of 15 minutes, stop the exercise, inform the cultural experts of all three rules, thank all volunteers for their participation, and process the exercise.

## IV. Processing the Exercise

- Allow both the cultural expert and mystery culture volunteers to share their experience as participants in the exercise, and their observations and feelings about what happened. Encourage the audience to contribute to the conversation. Some questions may be helpful to prompt discussion:

\* For the Mystery Culture Members:

- What was it like abiding by your “rules?”
- What was your comfort level during the interview by the cultural experts?
- What reaction did you have to the interview by the cultural experts?
- What resources and/or skills were you able to draw on to facilitate communication?





\* For the Cultural Experts:

- What was your impression of the responses you got to your questions?
- What did you consider as explanations for those responses?
- What resources and/or skills were you able to draw on to facilitate communication?
- What helped you identify the rule(s)?
- Once you identified a rule, did it change anything in your approach to the mystery culture members?

\* For everyone:

- What do we rely on when confronted with an unfamiliar situation?
- What are your recommendations for fostering communication in this situation?
- Are there any general statements about culture that can be derived from this exercise?
- Are you familiar with any cultures in which there are rules like those shared by members of the mystery culture?

Among the realizations that may emerge from discussion are the following:

- We use our own experiences and behavior to evaluate and “understand” interactions with others.
- There is a tendency to attribute a difficulty or barrier to the unfamiliar culture, e.g. “they don’t understand”, rather than “I am not communicating effectively.”
- Culture can be subtle. Some “rules” or behaviors may not be obvious, as might be the case with clothing or ornamentation.
- One’s demeanor may have a profound

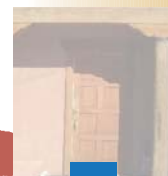
effect on communication.

- A minority culture may see advantages to adopting behaviors of a dominant culture.
- Participants may generate examples of the “rules.” In some cultures it is polite, or even required, to refrain from saying “yes” to something, even though it is the desired response, until you have been asked several times. Another example might be saying “yes” to avoid conflict. In still another example, listeners who do not get a desired response may convince themselves that “no” really means “yes.” In other cultures, genders are quite segregated from one another in many respects, perhaps including direct communication in public.

## V. Closing

Thank all volunteers again, as well as the audience, for their participation. Acknowledge the difficulty of the cultural expert role and note their contribution to building cultural awareness. Help diffuse and tendency on the part of some CE volunteers to feel ashamed or embarrassed that they were unable to identify all the rules.

Use this exercise to reinforce the importance of continuing to build cultural knowledge and skill toward a goal of enhanced cultural competency.





## Human Cultural Treasure Hunt

One of our greatest treasures is the people we work with, who commit themselves to making a difference in our fight against the HIV epidemic and in our support of individuals affected by HIV. In this treasure hunt, you will talk to your colleagues and identify one person in the group who fits each description below and have that person sign his or her name next to the description. Use a person's name only once.

- \_\_\_\_\_ has honored a *Dia De Los Muertos* activity
- \_\_\_\_\_ has been in a *Quinciniera*
- \_\_\_\_\_ was baptized in the Catholic Church
- \_\_\_\_\_ has a collection of artifacts representative of a specific culture (example: carved Santos, religious icons)
- \_\_\_\_\_ has traced family history back several generations, or before the Treaty of Guadalupe Hidalgo (1848)
- \_\_\_\_\_ has read the *Autobiography of Frida Kahlo*?
- \_\_\_\_\_ has actively worked to change a policy that disrespects a particular cultural belief or religious holiday
- \_\_\_\_\_ is part of a large, extended family
- \_\_\_\_\_ knows the origin of *Cinco De Mayo*
- \_\_\_\_\_ speaks both English and Spanish
- \_\_\_\_\_ routinely participates in a cultural ceremony
- \_\_\_\_\_ has consulted a *curandera*
- \_\_\_\_\_ is a *comadre* or *compadre*
- \_\_\_\_\_ prefers to identify as other than “Hispanic” or “Latino”
- \_\_\_\_\_ visits family in Mexico at least once a year
- \_\_\_\_\_ has experienced racial profiling
- \_\_\_\_\_ has witnessed *La Llorona*

Allow 15 minutes for this “icebreaker” exercise. Select 8-10 statements from above, or add your own; number and content will depend on the size and composition of the group, or the content of the program. Divide a large group into smaller groups. Consider inserting a question for which you can offer special recognition (published in the field, given an award for work in the Latino community, has a birthday in the current month, etc.). Debrief with informal discussion of what participants learned.





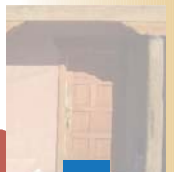
## Case Study Worksheets

**Case #1** - Gloria is a 70 year old Latina who was diagnosed with AIDS two months ago. She was recently hospitalized with Tuberculosis. Gloria lives in her own home with her boyfriend. Her family lives in the area. She has Medicaid. Gloria seems calm about her illness. She stated that she accepts it as part of life. Her present need is for home health care.

**What are the cultural issues or values that may influence how you work with Gloria?**

**What are the opportunities for teaching advocacy skills to Gloria?**

**What are some appropriate resources for Gloria?**





**Case #2** - Francisco is a 42 year old Latino. He identifies as heterosexual. He was diagnosed HIV positive four months ago at the local health department. Francisco reports being scared, although he denies being depressed. His girlfriend is his only support system. His family is out of state. Francisco does not have medical insurance. He reports no history of drug abuse. He has recently been treated for oral thrush. His presenting concern is insurance.

**What are the cultural issues or values that may influence how you work with Francisco?**

**What are the opportunities for teaching advocacy skills to Francisco?**

**What are some appropriate resources for Francisco?**





## Training Program Planning Guide

Training Site \_\_\_\_\_

Educator(s) \_\_\_\_\_

### I. ASSESSMENT

- A. How will you gather information to help you plan an education program that meets the learners' and the facility's needs?
- B. What would you like to know about your target audience?  
*(Consider prior HIV/AIDS education, population served by your audience members, job-related or personal concerns about HIV, ethnic identity of audience members, etc.)*
- C. Are there any barriers or constraints you must consider in planning your educational program?  
*(Consider available meeting space and time, target audience schedules, access to resources, support from administration, etc.)*
- E. What time and location schedule would you like to follow?  
*(Develop an agenda)*
- F. What resources do you need and who is responsible for securing them?
  - 1. Curriculum materials, handouts, overheads, slides, activity guides, etc.
  - 2. Equipment
  - 3. Additional resource people, such as co-presenters, guest speakers, facilitators, etc.
- G. How will you announce the program?
- H. Who will conduct evaluation? Bring necessary forms to complete evaluation?
- I. Do other responsibilities need to be assigned?

### II. PLANNING/PREPARATION

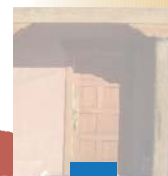
- A. Review assessment information above to determine program content.
- B. What planning process will you follow?  
*(Committee, as per job description, borrow developed program plan, collaboration with other staff or agencies, etc.)*
- C. What are the goals and objectives of the education program?  
*(What do you want learners to be able to do at the conclusion of your program? Are your objectives cognitive, attitudinal or behavioral?)*
- D. What is the most effective format for your presentation?  
*(Consider number and length of sessions, frequency and timeframe if more than one, sequence of information, etc.)*

### III. PRESENTATION

- A. Use assessment and goals and objectives to guide content and techniques.
- B. How will you hold your audience's attention?
- C. Does someone know how to operate the AV equipment, have contacts within the facility for assistance?
- D. Where is the flexibility in your schedule?

### IV. EVALUATION

- A. How will you know if you achieved your objectives?
- B. Is follow-up education indicated?
- C. Do you need to keep a record of or report on this education program?







## Appendix II Information and Referral Resources

### Websites

#### AIDS Info

<http://www.aidsinfo.nih.gov>

This is a new website that merges the Clinical Trials Information Service (formerly at [www.actis.org](http://www.actis.org)) and the HIV/AIDS Treatment Information Service (formerly at [www.atis.org](http://www.atis.org)). It is comprehensive, and provides access to guidelines for treatment of: HIV with antiretrovirals, maternal child transmission, pediatric HIV, post-exposure prophylaxis, opportunistic infections, tuberculosis, and HIV testing and counseling guidelines. Also provides information on drugs, federally and publically funded clinical trials, vaccines, a glossary, and links to other sources.

#### AIDS Treatment Data Network

<http://www.atdn.org>

New York-based CBO website offering *Simple Facts* Information Sheets - information on drugs and diseases in AIDS in non-clinical language, in English and Spanish. Tel: 800-734-7104

#### AIDS Treatment News Internet Directory

<http://www.aidsnews.org>

A comprehensive index, organized by topics, of AIDS treatment websites, Internet resources and links, conference coverage and reports, special topics (e.g., legal, prison, women), treatment and drug information, ask expert sites and medical education.

#### American Foundation for AIDS Research

<http://www.amfar.org>

The American Foundation for AIDS Research (AMFAR) is a national nonprofit organization created to support AIDS research. This site provides information about AmFAR and the research it funds. Tel: 800-764-9346

#### American Red Cross

<http://www.redcross.org/hss/hiv aids>

Designed primarily as an educational resource for the general public, this site provides basic information about AIDS. Special materials for training in the Hispanic community are available. Tel: (202) 737-8300

#### Association of Nurses in AIDS Care

<http://www.anacnet.org/aids>

The Association of Nurses in AIDS Care (ANAC) is a national, nonprofit organization for nurses who work with AIDS patients.

#### The Body

<http://www.thebody.com>

This is a patient-friendly HIV/AIDS information resource containing a 20,000 document library of in-depth information on every aspect of diagnosis and treatment.





### Centers for Disease Control and Prevention

[http://www.cdc.gov/nchstp/hiv\\_aids.htm](http://www.cdc.gov/nchstp/hiv_aids.htm)

Division of HIV/AIDS Prevention

<http://www.cdc.gov/hivsitemap.htm>

General information, surveillance data and prevention resources on a wide variety of diseases, including HIV/AIDS. Phone: Tel: (404) 639-3311

### CDC National Prevention Information Network

<http://www.cdcpin.org>

Sponsored by the CDC, this organization was formerly known as the National AIDS Clearinghouse. This site provides thousands of links to HIV-related sites, organizations, and publications. Updated daily, provides daily electronic information..

### Gay Men's Health Crisis

<http://www.gmhc.org>

Based in New York City, Gay Men's Health Crisis is the oldest and largest nonprofit AIDS organization in the U.S. It supplies aid for local HIV patients and their families while providing education and advocacy worldwide. Tel: (212) 807-6664

### Journal of the American Medical Association

<http://www.ama-assn.org/special/hiv>

The Journal of the American Medical Association (JAMA) HIV/AIDS Information Center offers a wide range of clinical information for physicians and other health care professionals. Tel: (312) 645-5000

### National AIDS Treatment Advocacy Project

<http://www.natap.org>

Current coverage and reports from major HIV and HCV-related conferences, a large collection of articles, patient resources and audio clips from an HIV and HCV-focused radio program. An extensive amount of material on HIV-HCV co-infection.

### National Association of People with AIDS

<http://www.napwa.org>

Tel. 800-673-8538

### National Center for Complementary and Alternative Medicine

<http://www.nccam.nih.gov>

### National Clearinghouse for Alcohol and Drug Information

<http://www.health.org>

Center for Substance Abuse Prevention. Tel. 800-729-6686

### National Clearinghouse for Alcohol and Drug Information

<http://www.health.org>

Center for Substance Abuse Prevention. Tel. 800-729-6686

### National Library of Medicine

<http://sis.nlm.nih.gov/hiv.htm>

This is a comprehensive site with tutorials on researching HIV/AIDS; information on HIV/AIDS training and outreach programs; publications, such as fact sheets, manuals, and bibliographies and links to other sites. This is an excellent site for professional research. Access to Pub Med.

For a free information packet, call 800-638-8480.





### New Mexico AIDS Infonet

<http://www.aidsinfonet.org>

Excellent source for patient information materials in both English and Spanish. Current, comprehensive, and user-friendly.

### University of California at San Francisco

<http://hivinsite.ucsf.edu/>

HIV treatment, research, prevention, statistics, and interactive question and answer service, and scrolling current facts. Content is arranged by key topics, e.g., adolescents, substance use, etc.).

## Hispanic Health Sites

### The National Alliance for Hispanic Health

([www.hispanichealth.org](http://www.hispanichealth.org))

Since 1973 providing information about Hispanic health to consumers and providers with up-to-date reports on national policy, science, and technology

### COSSMHO

[www.cossmho.org](http://www.cossmho.org)

The National Coalition of Hispanic Health and Human Services Organizations - is a nonprofit membership organization dedicated to improving the health and psychosocial lives of Hispanics.

### National Minority AIDS Council

[www.nmac.org](http://www.nmac.org)

NMAC is a national organization dedicated to developing leadership within communities of color to address the challenges of HIV/AIDS. Services include, conferences, policy, information, and technical assistance. Tel: (202) 483-6622

Several previously listed sites provide materials in Spanish. Key sites include:

### AIDS Treatment Data Network

<http://www.atdn.org/lared/index.html>

### New Mexico AIDS Infonet

<http://www.aidsinfonet.org/infored.html>

### Project Inform

<http://www.projinf.org/spanish>

### San Francisco AIDS Foundation

<http://www.sfaf.org/espanol.html>

HIV Information Line - (800) 333-2437

## Additional Resources

### Teen AIDS Hotline

800-283-2473

### National Sexually Transmitted Diseases Hotline/CDC

800-227-8922

### Women and AIDS Resource Network

PO Box 020525 Brooklyn NY 11202 Tel:  
(718) 596-6007





## Colorado Resources

### Colorado AIDS Education & Training Center

<http://www.uchsc.edu/sm/aids/colorado.htm>

University of Colorado Health Sciences  
Center

4200 East Ninth Avenue, Box A-089

Denver, CO 80262

(303) 315-2516 (303) 315-2514 (fax)

### Southern Colorado AIDS Project

<http://www.S-cap.org>

1301 South Eighth Street, Suite 200

Colorado Springs, CO 80906

(719) 578-9092 (719) 578-8690 (fax)

Direct client services for those living with  
HIV/AIDS as well as prevention.

Pueblo Office:

2001 Oakland Avenue

Pueblo, CO 81004

(719) 561-2616 (719) 561-4857 (fax)

For Office in Alamosa please contact  
Springs or Pueblo Office above. Please  
note there are other regional CAPS  
throughout Colorado. For a list of other  
CAPS, please contact SCAP.

### Colorado Department of Education

[http://www.cde.state.co.us/index\\_home.htm](http://www.cde.state.co.us/index_home.htm)

AIDS Prevention Project

201 East Colfax Avenue, Room 405

Denver, CO 80203

(303) 866-6766 (303) 866-6785 (fax)

### Colorado Department of Health

<http://www.cdphe.state.co.us/cdphehom.asp>

STD/AIDS Education and Training  
Program

4300 Cherry Creek Drive, South, 3rd Floor

Denver, CO 80222

(303) 692-2720

### Pueblo County Health Department

151 Central Main Street

Pueblo, CO 81003

(719) 583-4800

### Health Resources Services Administration

AIDS Coordinator

1961 Stout Street, Room 409

Denver, CO 80294

(303) 844-3206 (303) 844-0002 (fax)

### Latin American Research and Service Agency

<http://www.larasa.org>

(LARASA)

309 West First Ave.

Denver, CO 80223-1509

(303) 722-5150 (303) 722-5118 (fax)

### Mi Casa Resource Center for Women, Inc

<http://www.micasadenver.org>

571 Galapago St.

Denver, CO 80204-5032

(303) 573-1302 (303) 455-0422 (fax)

### Servicios de La Raza, Inc.

4055 Tejon St.

Denver, CO 80211

(303) 458-5851 (303) 455-1332 (fax)





## Appendix III

### Glossary

**Abstinence:** To voluntarily refrain from engaging in some activity; to do without or practice self-restraint. With respect to HIV, most applicable to sexual intercourse and/or substance use.

**Acculturation:** Cultural modification of an individual, group, or people by adjusting to or borrowing traits from another culture, and integrating them with one's own culture.

**Acquired immunodeficiency syndrome (AIDS):** The late stage of HIV disease, which is diagnosed by the development of specific opportunistic infections, cancers, or CD4 counts of less than 200 cells/mL, in the presence of HIV infection.

**Acute:** Reaching a crisis quickly; very sharp or severe.

**Acyclovir:** A drug used to treat herpes.

**AIDS:** See Acquired Immunodeficiency syndrome.

**Alternative Therapies:** Non-medical approaches that some people believe to be effective in treating HIV infection; these include acupuncture, visualization, crystals, nutritional therapy and macrobiotics. In Hispanic/Latino culture examples of alternative therapies are cuanderismo (folk healing), espiritismo (spiritism), and Santeria (the religion of the saints).

**Amphotericin B:** A drug used to treat HIV opportunistic infections, such as candidiasis (thrush) and cryptococcosis.

**Anal sex (also anal intercourse):** Inserting the penis into the anus of the sexual partner. May be practiced as a form of birth control or to preserve virginity.

**Anonymous testing:** HIV antibody testing procedure that does not require disclosure of personal identifying information. Results are coded.

**Antibody:** A substance in the blood that forms when disease agents such as viruses, bacteria, fungi, and parasites invade the body.

**Antibody-negative test results:** An HIV antibody test result that does not register or detect the presence of antibodies to HIV, which may be either because the person does not have HIV, or the person has become infected with HIV too recently to have detectable antibodies.

**Antibody-positive test:** An HIV antibody test result that detects the presence of antibodies to HIV, indicating infection with HIV. The 3-step protocol must be followed to have a positive result.

**Anus:** The ring of muscle at the opening of the rectum that controls release of waste (feces) from the body.

**Assimilate:** The acceptance by one social group or community of cultural traits normally associated with another.

**Asymptomatic HIV:** Infection with HIV without symptoms of disease.

**Autologous blood donation:** Donation of one's own blood to store for elective surgery.





**Bacteria:** Microscopic organisms that cause disease.

**Bacterial infections:** The diseases that bacteria causes; most respond to antibiotic treatment.

**Bactrim®/Septra:** Also TMP/SMX (trimethoprim sulfamethoxazole). A common antibiotic used to treat and/or prevent PCP and other bacterial infections.

**B-cell:** A type of white blood cell that makes antibodies against disease agents in the body.

**Bisexual:** A person whose sexual orientation is to both genders; one who is emotionally and physically sexually attracted to and comfortable with persons of both male and female genders.

**Blood-borne disease:** Infections whose disease agents are carried in the blood stream (for example, Hepatitis B, Hepatitis C, and HIV infection).

**Blood-clotting factors:** Substances in the blood that cause it to thicken (clot) and change from a liquid to a solid; used to treat hemophilia.

**Blood components:** The parts of the blood, including formed elements (white blood cells, red blood cells, and platelets) and liquid (plasma) that contain proteins used to make clotting factors.

**Blood testing:** Taking a small sample of a person's blood, which is then examined to determine blood characteristics, or to enable detection of disease agents or evidence of infection.

**Blood-to-blood-contact:** A means that allows blood from one person to enter the bloodstream of another; a mechanism for transmitting disease.

**Body fluids:** Fluids produced by humans, such as blood, semen, vaginal secretions, and breast milk (high risk for HIV) and tears, saliva, and sweat (low risk for HIV).

**Candidiasis:** A fungal infection that occurs in several places in the body, including the mouth or throat (thrush), in the vagina (yeast), or on the skin; a common opportunistic infection in people with HIV disease.

**Casual contact:** Ordinary, non-invasive, social contact, such as kissing the cheek; shaking hands; using the same telephone, toilet, or swimming pool; or working in the same office. Casual contact does not spread HIV.

**CD4 cell:** A type of immune system T cell involved in protecting against viral, fungal and protozoal infections. These cells normally orchestrate an immune response, signaling other immune system cells to perform their special function.

#### **Centers for Disease Control and**

**Prevention (CDC):** An agency of the U.S. Department of Health and Human Services, with a mission to promote health and quality of life by preventing and controlling disease, injury and disability.

**Cervix:** The lower part of the uterus, extending into the vagina; contains a narrow canal connecting upper and lower parts of a woman's reproductive tract.

**Chlamydia:** A non-gonococcal urethritis (NGU), a common sexually transmitted bacterial disease.

**Chronic:** A prolonged, lingering, or recurring state of disease.

**Cinco De Mayo:**





**CMV/Cytomegalovirus infection:** A viral infection that may occur without any symptoms and may result in mild flu-like symptoms; a common opportunistic infection among people with AIDS, it often causes loss of sight.

**Communicable Disease:** A disease that can be transmitted.

**Condom:** A sheath, generally made of latex or polyurethane, that fits over the erect penis to prevent release of ejaculate into a partner; protects against many disease; a form of birth control.

**Confidential Testing:** HIV antibody testing procedure that requires disclosure of identifying information that is linked to test results. Facilitates partner notification.

**Confidentiality:** Respecting privacy, not disclosing personal information, protecting identity.

**Contact Tracing/Partner Notification:** The process of letting sexual and injecting-partners of an HIV-infected person know they may have been exposed to HIV.

**Contaminated Needles:** Used here to mean needles that have been used by someone with HIV and then improperly cleaned or disposed of.

**Crack:** A form of Cocaine that is smoked.

**Crack House:** A place where Crack is bought and used.

**Cryptosporidiosis:** An opportunistic infection that can occur in people with HIV/AIDS; caused by a parasite. Its primary symptom is diarrhea. Also cryptosporidium.

**Cytomegalovirus infection:** see CMV

**Culture:** patterns of human behavior, including thoughts, actions, customs, values, beliefs, artifacts, language, experiences and conditions that bind racial, ethnic, religious or social groups within a society.

**Curanderismo:** A Hispanic/Latino practice through which curanderos (healers) use spiritual or herbal therapies or prayer to cure illness or evils.

**Designated blood donation:** Blood that a family or friend donates for a specific person's use or purpose.

**Developed Immunity:** Induced protection against an infection, through immunization or disease exposure.

**Dia De Los Muertos:**

**Disease agent:** A foreign body, such as a virus, bacterium, fungus, or parasite, that causes infection or disease; sometimes also called a germ.

**Disinfectant:** A chemical that destroys disease agents.

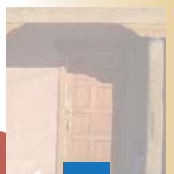
**Donor:** Someone who gives blood, other body substance, tissue or organ.

**Ejaculate:** The fluid released from the penis during orgasm.

**Ejaculation:** The spontaneous discharge of semen during orgasm.

**ELISA:** Enzyme-linked immunosorbent assay, sometimes abbreviated EIA, used to detect the presence of antibodies to HIV in blood or oral fluids/secretions.

**Epidemic:** A disease that spreads rapidly through a given geographic area.





**Espiritismo(Spiritism):** A Hispanic/Latino belief which may combine Spanish, African and indigenous folk healing practices based on the premise that the visible and invisible worlds are inhabited by spirits that reside temporarily in a human body.

**Ethnocentrism:** To judge other cultures by the standards of one's own, usually perceiving other cultures negatively.

**Experimental drug:** A drug that is in the process of being scientifically tested but is not yet approved or licensed by the Food and Drug Administration for general use.

**Exposure to (HIV):** When someone is unprotected from the kind of contact (sexual or blood-to blood) that spreads HIV.

**FDA:** See Food and Drug Administration.

**False-negative test:** An antibody test for HIV that shows negative results even though the blood sample contains the virus; uncommon, usually found only in people recently infected with HIV who as yet have no detectable antibodies.

**False-positive test:** Positive HIV antibody test in the absence of HIV. Can occur in some diseases.

**Fatalism:** The belief that many things that happen to people in their lives are beyond their control. Expressions such as its "God's will," "Everyone has a cross to bear," "and it's fate- there's nothing that can be done," demonstrate this attitude of resignation.

**Feces:** Solid bodily waste discharged through the anus.

**Fellatio:** Mouth-to penis sex. See Oral sex.

**Food and Drug Administration/FDA:** An agency of the U.S. Department of Health and Human Services, responsible for ensuring the safety and efficacy of all drugs, biologics, vaccines and medical devices, including those used in diagnosis, treatment and prevention of HIV.

**Fungus:** Microscopic disease organisms, including yeasts and molds.

**Ganciclovir:** A drug used to treat cytomegalovirus infection.

**Gene:** A unit of DNA, arranged on a chromosome, that carries information; the unit by which inheritable characteristics are transmitted; basic unit of heredity; gene alterations create mutations.

**Genital contact:** Contact between the sexual organs of two people.

**Genital warts:** A common sexually transmitted disease, caused by human papilloma virus (HPV), that cannot be cured. Spread during vaginal, anal and oral sex with someone who has genital warts. After genital warts go away, the virus stays in the body. The warts can come back.

**Genotypic Assay:** A test used to identify gene mutations that indicate whether HIV/AIDS medication are working; i.e., a test for HIV resistance to drugs.

**Gonorrhea:** A treatable, common sexually transmitted infection; can also be transmitted to newborns during childbirth.

**HAART(highly active antiretroviral therapy):** An HIV/AIDS treatment regimen consisting of three or more antiretroviral medications.





**Hemophilia:** A hereditary blood disorder that prevents blood from clotting properly.

**Hepatitis:** An inflammation of the liver that may be caused by bacterial or viral infection, parasitic infestation, alcohol, drugs, toxins or transfusion of incompatible blood. Treatment and course of disease depend on type.

**Hepatitis A (HAV):** A viral hepatitis infection transmitted through fecal/oral contact, often via food handling or through water. Vaccine available.

**Hepatitis B (HBV):** A viral hepatitis infection, most commonly transmitted through intercourse, especially unprotected anal sex, or percutaneously by sharing drug needles. Vaccine available, but can be acute, chronic or fatal

**Hepatitis C (HCV):** A viral hepatitis infection that is primarily bloodborne, transmitted percutaneously via contaminated needles; may also be sexually transmitted. No vaccine available. A common co-infection in a person with HIV/AIDS.

**Herpes Simplex Virus (HSV):** Shortened to herpes, a family of viruses that cause fluid-filled blisters around the mouth (usually HSV I) or genitals (usually HSV II). Latent virus may be reactivated by stress, trauma, other infections, immune suppression. Transmitted by contact.

**Heterosexual:** Being physically, romantically or sexually attracted to people of the opposite gender/sex. Also, having sexual partners of the other sex.

**HIV:** See Human Immunodeficiency virus.

**Homosexual:** Being romantically or sexually attracted to people of the same sex; gay/same gender loving people. Also, having sexual partners of one's own sex.

**Hospice:** A program offering compassionate care in the home or in a residential facility for terminally ill people preparing to die.

**Household contact:** Ordinary social contact among members of a household. See casual contact.

**Human immunodeficiency virus (HIV):** The virus that causes AIDS; HIV destroys the body's immune system, making it easier for life threatening opportunistic infections or cancers to invade the body.

**IDU:** See Injection drug use.

**Immune:** Protected from disease.

**Immune system:** A variety of cells and substances within the body that help resist foreign invaders such as viruses, bacteria, parasites, and fungi.

**Immunization:** Triggering the body's self-defense immune system against infection through vaccination.

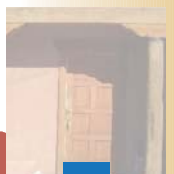
**Incidence:** The number or rate of new cases of a disease in a defined population over a specific period of time.

**Infection:** Invasion of the body by a disease causing agent.

**Infectious disease:** A disease that is caused by or can be transmitted by a foreign agent; usually contagious or communicable to other.

**Injection-drug use/IDU:** Use of a needle and syringe to inject drugs or other substances, e.g., steroids, vitamins, into the body tissue. Injections may be into veins, muscles, or under the skin ("skin popping").

**Intercourse:** See sex.





**Kaposi's sarcoma/KS:** An illness defined by cancerous lesions caused by overgrowth of blood vessels. Usually on the skin surface or mucous membranes in the mouth; can also occur internally in the intestines, lymph nodes or lungs. Appears as red or purplish spots.

**La Llorona:**

**Lesbian:** A woman who is romantically or sexually attracted to women. Same gender loving people.

**Lesion:** An abnormal change in the tissue or in the structure of an organ or body part due to injury or disease; Lesions include macules, vesicles, blebs, or bullae, chancres, pustules, papules, tubercles, wheals, and tumors.

**Lipodystrophy:** The loss of fatty tissue, particularly in the legs, arms, and face. The term is frequently used to describe any type of body fat redistribution. A side effect of HIV/AIDS medication that is associated with Protease inhibitors (PI) and Highly active antiretroviral therapy (HAART).

**Lubricant:** A substance used to reduce friction during sex. Water based lubricants are recommended as opposed to oil based lubricants.

**Lymph glands:** Glands located in the groin, neck, armpits, and elsewhere containing large numbers of lymphocytes that fight infection. May also be reservoirs for HIV infection.

**Lymphocytes:** Certain types of white blood cells called t-cells/CD4 T-cells and B-cells; essential to the function of the immune system.

**Lymphoma:** A usually malignant lymphoid tumor.

**Machismo:** Refers to traditional Hispanic/Latino culture male attributes such as masculinity, invulnerability, and dominance; may include control over sexual relationships, rejection of homosexuality, and obligation to maintain and protect the family.

**Marianismo:** The term marianismo refers to the devotion that many Hispanics/Latinos feel toward the Virgin Mary. The term is used in reference to the stereotype of the Hispanic/Latina: submissive, virtuous, tolerant, self-sacrificing, and devoted to serving the male figure in her life.

**Masturbation:** Massaging one's own genitals, often to the point of orgasm.

**Medicaid:** A federal-state health insurance program that pays certain medical expenses for people whose income falls below the poverty level as set by each state.

**Medicare:** A federal health insurance program that pays certain medical expenses for people who are disabled, over 65, or suffering from chronic disease.

**Meningitis:** Infection and inflammation of the membranes that cover the brain and spinal cord.

**Menstruation:** The monthly shedding of the uterus lining during the menstrual period.

**Metabolic disorder:** Dysfunction in metabolism, which are cellular chemical changes that provide energy for vital processes and activities.

**Mucous membrane:** A lining or membrane of all the body passages that have an outside opening, e.g., both the lining of the mouth the vagina.





**Mutating virus:** A virus that changes genetic structure during cell replication. HIV/AIDS is a mutating virus.

**Mutual masturbation:** Massaging a partner's genitals, often to the point of orgasm.

**National Institutes of Health (NIH):** An agency of the U. S. Department of Health and Human Services that supports and conducts biomedical and health research

**Needle stick:** A needle puncture of the skin, often accidental.

**Negative test results:** The finding of a test that detects no signs of antibodies to HIV; a negative test result can mean that someone is not infected but also can mean that the person was too recently infected to have detectable antibodies. See False-negative test.

**Neuropathy:** A group of disorders involving nerves; symptoms may include pain, burning, aching, weakness or pins and needles in the extremities; a side effect of some medications.

**NNRTIs (Non-nucleoside reverse transcriptase inhibitors):** A class of antiretroviral drugs similar to NRTIs. NNRTIs stop HIV production by binding directly on to reverse transcriptase and preventing the conversion of RNA to DNA.

**NRTIs (Nucleoside reverse transcriptase inhibitors):** A class of HIV antiretroviral drugs used to treat HIV infection. NRTIs suppress viral replication by interfering with the reverse transcriptase enzyme found in HIV.

**Opportunistic infections:** Illnesses caused by various organisms, some of which do not cause disease in people with normal immune systems.

**Oral sex (oral intercourse):** Contact of the mouth or tongue with a partner's penis, vagina, or anus during sexual activity.

**Pandemic:** A disease that occurs throughout an entire country, continent or the whole world.

**Parasite:** An organism that relies upon another organism for survival, causing some harm to the host organism.

**Parenteral transmission of (HIV):** A route other than in or through the digestive system; introduction of HIV into the body through transfusion or injection into a vein, muscle or under the skin.

**Partner Notification:** The process of letting sexual and needle-sharing partners of a HIV-infected person know they may be at risk of having HIV. (See also Contact tracing).

**Penis:** The male sexual organ.

**Perinatal transmission (of HIV):** Passing HIV to an infant before, during, or after birth.

**Phenotypic Assay:** Used to test a person's HIV DNA against various antiretroviral drugs to determine if the virus is resistant to the drugs; used to detect resistant mutation in the HIV/AIDS virus.

**PIs (Protease Inhibitors):** A class of antiretroviral drugs used to treat HIV infection. PIs block the action of the HIV protease enzyme, resulting in a reduction of viral replication (the reproduction of HIV).

**Placenta:** The blood-filled organ that connects the fetus to the mother's body by the umbilical cord; the source of nutrition for the fetus.





**Pneumocystis carinii pneumonia (PCP):** A form of pneumonia caused by a parasite that rarely affects people with fully functioning immune systems. PCP is an opportunistic infection common to people with AIDS.

**Pneumonia:** An infection of the lungs.

**Polymerase chain reaction test (PCR):** A test that can detect HIV by looking for the genetic information of the virus; this test can find the virus even if it is present only in very small amounts or is hidden inside the white blood cells. .

**Positive test result:** The findings that show the presence of HIV antibodies; the person tested is assumed to be infected with HIV and able to infect others.

**Prevalence:** Total number of cases of a disease in a population over a period of time.

**Prophylaxis:** Preventive treatment.

**Quinciniera:** An often elaborate Mexican celebration of a young girl's 15th birthday.

**Rectum:** The last portion of the digestive tract, just above the anus.

**Respite care:** Short-term care of chronically ill people provided to give their caregivers some time off.

**Risk behavior:** Activities that put people at increased risk of getting HIV.

**Safe sex:** Sexual practices that involve no exchange of blood, semen, or vaginal fluid.

**Saliva:** The fluid produced in the mouth.

**Salvage therapy:** A later (3<sup>rd</sup> or 4<sup>th</sup>) ART drug regimen prescribed to individuals who have failed earlier drug therapies due to resistance.

**Santeria “the religion of the saints”:** A New World religion that emerged from the fusion of ancient religions brought to the Caribbean by West African slaves and Catholic beliefs brought by the Spanish.

**Semen:** Whitish fluid containing sperm, white blood cells, and fluid, which is ejaculated from the penis during orgasm.

**Septra/Trimethoprim:** A drug used to treat PCP.

**Seroconversion:** The development of antibodies to a particular antigen. In HIV infection, the antibodies normally appear within 2 to 12 weeks of infection and may produce a flu-like illness.

**Serology:** Study of the clear fluid portion of blood; testing for antibodies is serologic testing.

**Sex (also sexual intercourse):** Genital/oral contact between individuals; contact with vagina, penis, or anus.

**Sexual orientation:** The genetic disposition (attraction, feelings) one has toward others of their own sex, of the opposite sex, or of both sexes.

**Sexually transmitted disease (STD):** A disease that spreads during sex, through genital/oral contact between people; for example, gonorrhea, syphilis, herpes, and HIV infection are STDs.

**Shingles:** The common name for herpes varicella zoster, an inflammation of nerve endings brought about by the same virus that causes chicken pox; an opportunistic infection common to people with AIDS.

**Shooting galleries:** Places where drugs are sold and used, particularly injection drugs.





**Shots:** See Immunization.

**Snorting (cocaine):** Inhaling (cocaine).

**Speedball:** Heroin mixed with amphetamines (speed) or cocaine.

**Spend down:** To qualify for Medicaid by having medical bills that reduce one's income below the poverty level.

**Sperm bank:** A storage facility for sperm before it is used in artificial insemination.

**Spermicide:** A chemical usually found in the form of a foam, cream, or jelly that kills sperm on contact.

**SSI:** Supplemental Security Income: A welfare program under Social Security for people who are disabled, elderly, or blind; some benefits or temporary benefits under this program may be available to people with HIV.

**SSDI:** Social Security Disability Insurance: A form of federal insurance; payment is related to the amount of money a person has paid into the Social Security system.

**STD:** See Sexually transmitted disease.

**Stigma:** A mark of shame or discredit that sets a person apart from others. HIV/AIDS is not just any disease. Because it's associated with sexual behavior and drug use, people may react to it in a number of different ways.

**Syndrome:** A group of related problems or symptoms.

**Syphilis:** A sexually transmitted disease that causes sores on the genitals and, if untreated, may lead to heart and brain damage.

**T-cell/CD4 T-cell:** A type of white blood cell essential to the body's immune system; helps

regulate the immune system including control of B- cells and macrophage functions.

**Test sensitivity:** The likelihood that infected people will test positive.

**Test specificity:** The likelihood that uninfected people will test negative.

**Thrush:** See Candidiasis.

**Toxic:** Refers to the harmful side effects common with HIV medications.

**Toxoplasmosis:** Infection caused by a protozoan parasite found in soil contaminated by cat feces, or in meat, particularly pork. Can infect lungs, retina of the eye, heart, pancreas, liver, colon or testes. The most common infection site in HIV + persons is the brain.

**Transfusion (blood):** The transfer of compatible blood or blood products from one person to another; transfusing fluid into a vein.

**Transplant:** The transfer of an organ or tissue from one person to another.

**Tuberculosis (TB):** A contagious disease that primarily affects the lungs; an opportunistic infection common to many people with AIDS.

**Urine:** Fluid waste excreted by the kidneys.

**Vaccine:** A substance made from modified or denatured viruses or bacteria that helps to protect people against a particular disease.

**Vagina:** The passageway in the female extending from the vulva to the cervix; is penetrated in vaginal sex.





**Vaginal fluid:** Fluid that provides moistness and lubrication in the vagina; vaginal fluid of an HIV-infected woman may contain HIV.

**Vaginal sex (also vaginal intercourse):** Penetration of the vagina, by for example, the penis or a sex toy.

**Vaginitis:** A yeast infection in women caused by the same fungus, *Candida albicans*, that causes thrush. A discharge that often resembles cottage cheese and severe genital itching are symptoms of vaginal yeast infections. Vaginal yeast infections are common in all women but are especially common in women with HIV infection.

**Viral load:** This refers to the quantity of HIV found in the blood. Viral load is determined by measuring the level of HIV RNA, an indicator of how much HIV is reproducing in the body. Changes in viral load are used to determine whether or not antiretroviral therapy is working.

**Virus:** A disease agent that must live within cells of the body, often destroying these cells; much smaller than bacteria.

**Wasting syndrome:** The extreme weight loss (more than 10 percent of body weight) that often affects people with AIDS.

**Western blot:** A blood test that can detect antibodies to HIV; used to confirm ELISA results.

**White blood cell:** A type of blood cell whose primary function is to fight infection; white blood cells include T-cells, B-cells, and macrophages.

**Window period:** The period between infection with HIV and detection of antibodies to HIV through standard HIV antibody testing; from 2 to 12 weeks.

**Works:** Needles, syringes, and other equipment used to "cook" or prepare and inject street

